"We live in the future": An ethnography of chronic pain in North East England

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Abstract

This thesis is an ethnography of chronic pain in North-East England. It is based on approximately 14 months of online and in-person fieldwork, undertaken during the Covid-19 pandemic. In it, I focus on the lives of women who 'live under' (Martin, 2007) the diagnosis of chronic pain in the North-East. The basis for undertaking this project was the documented 'pain divide' (Todd *et al.,* 2018) which exists between North-East England and the rest of the country, alongside the many other embedded examples of health inequity which disproportionately impact the North-East. Throughout this piece of work, I focus on how my participants experience health inequity in their everyday lives. I take the stance that while these inequities are inherently structural in nature, they can be articulated through exploring different aspects of everyday life.

In this thesis, I demonstrate how living with chronic pain alters a person's relationship to time. The main body of this work is split into three main sections; the past, the present, and the future. In the first I explore how chronic pain changes a person's understanding of their past, both in terms of understanding violent life experiences, and through the 'diagnosis histories' used to explain how diagnoses came into existence. In the second section I demonstrate some of the different facets of navigating the present while living with pain: clinical encounters, sex and gender, taking different substances, and navigating social welfare systems. Finally, in the third section, I outline how people who live under the diagnosis of chronic pain anticipate and hope for better futures.

I draw three main conclusions from this thesis. Primarily, I conclude that living under a diagnosis of chronic pain changes a person's relationship to time. Importantly, this altered temporality changes how people understand the aetiology of their diagnosis, and also how they understand their own biology in relation to this aetiology. Secondly, and linking to this first concluding point, I argue that medical anthropologists need to 'take biology seriously' (Wilson, 2015: 13) in their ethnographic analyses of chronic pain, and around understandings of illness more broadly. Finally, with all this in mind, I argue thinking about chronic pain and its treatment using this biological mindset can help medical anthropologists to combine perspectives from the anthropology of pharmaceuticals and the anthropology of drugs.

I also offer some practical conclusions. Firstly, I argue that insights from structural violence could help to create systems of chronic pain care which are more effective. Secondly, this thesis highlights the contradictions which emerge when a person with chronic pain attempts to seek state welfare benefits. This thesis is oriented towards disability justice. As such, it provides evidence that theoretical and practical changes to the way disability is approached could provide better clinical and social care for people living under the diagnosis of chronic pain.

“We live in the future”: An ethnography of chronic pain in North East England

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A thesis submitted in fulfilment of the requirements for the degree of **Doctor of Philosophy**

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LIST OF ABBREVIATIONS

ADHD: Attention Deficit Hyperactivity Disorder
A&E: Accident and Emergency
BPD: Borderline Personality Disorder
CBD: Cannabidiol
CCG: Clinical Commissioning Group
CMHT: Community Mental Health Team
CRPS: Complex Regional Pain Syndrome
DLA: Disability Living Allowance
DWP: Department for Work and Pensions
EDS: Ehlers-Danlos Syndrome
ESA: Employment Sickness Allowance
GP: General Practitioner
HIV/AIDS: Human Immunodeficiency Virus/Acquired Immunodeficiency Syndrome
IBS: Irritable Bowel Syndrome
ICD: International Classification of Disease
IMD: Index of Multiple Deprivation
IV: Intravenous
JSA: Job Seekers Allowance
LA: Local Authority
LSAO: Lower Super Output Area
MDT: Multidisciplinary Team
ME: Myalgic encephalomyelitis
MS: Multiple sclerosis
NHS: National Health Service
NICE: National Institute for Clinical Excellence
NSAID: Non-Steroidal Anti Inflammatory Drug
OAT: Opioid Agonist Treatment
OTC: Over-the-counter
PIP: Personal Independence Payment
SMI: Severe Mental Illness
STS: Science and Technology Studies
TENS: Transcutaneous Electrical Nerve Stimulation
UC: Universal Credit

GLOSSARY OF SUBSTANCES

Amitriptyline: Amitriptyline is a generic tricyclic antidepressant also prescribed for chronic pain. Tricyclic antidepressants are an older class of antidepressants, developed in the 1950s. It is available on prescription only in the UK. It comes in tablet or liquid form.

Buprenorphine: Buprenorphine is a generic, high strength opioid painkiller (brand name Butec). It is most often administered via a patch that is stuck to the skin, and is available only on prescription in the UK. It is also an OAT used in the treatment of opioid addiction.

Buscopan: Buscopan is a brand name IBS medication (generic form: hyoscine butyl bromide). It is available in tablet form both OTC and on prescription in the UK.

Cannabis: Cannabis is a plant-based illegal drug. It is a class B drug in the UK, meaning that its possession can result in a maximum 5-year prison sentence. However, in 2015, Durham police announced they would stop pursuing people who possess small amounts of the drug for the purposes of personal use (Gayle, 2015).

Codeine: Codeine is a generic, medium strength opioid painkiller. It can be swallowed as a tablet or liquid, or injected. It is available only on prescription in the UK.

Co-codamol: Co-codamol is a generic, low strength opioid painkiller. It is a mix of codeine and paracetamol. It is available in tablet form both OTC and on prescription in the UK.

Duloxetine: Duloxetine is a generic antidepressant. It is a serotonin-noradrenaline reuptake inhibitor (SNRI). It is also prescribed to treat nerve pain and fibromyalgia. It is available only on prescription in the UK, and comes in capsule form.

Fluoxetine: Fluoxetine is a generic antidepressant. Its brand name is Prozac. It is a selective serotonin reuptake inhibitor (SSRI). It is available only on prescription in the UK, in tablet, capsule or liquid form.

Gabapentin: Gabapentin is a generic gabapentinoid medication used to treat epilepsy, anxiety, and nerve pain. It is available on prescription only. It comes as tablets, capsules, or a liquid.

Heroin: Heroin is an illegal drug. It is also known as diamorphine (two morphine molecules bonded together). It is a class A drug in the UK, meaning that its possession can result in a maximum 7 year prison sentence. It is not available on prescription in the UK, although certain preparations of diamorphine are occasionally used in end-of-life care.

Ibuprofen: Ibuprofen is a generic NSAID. It is available OTC as tablets, capsules, granules, gels, creams, and sprays.

Methadone: Methadone is a synthetic, generic OAT. It comes as a green liquid when being used to treat opioid addiction, or as tablets or injections when used during end of life care. It is available only on prescription in the UK.

Morphine: Morphine is a generic, high strength opioid painkiller. It comes as tablets, capsules, granules, liquid, or an injection. It is available on prescription only. In this thesis, you will commonly see morphine being referred to as Oramorph, which is the brand name for the liquid form.

Nabilone: Nabilone is a generic synthetic cannabinoid painkiller. It is only available via prescription in the UK. Its chemical structure is similar to that of cannabis. It is prescribed in capsule form, usually to aid chemotherapy nausea.

Naproxen: Naproxen is a generic NSAID. It is available only on prescription in the UK, as capsules or in liquid form.

Paracetamol: Paracetamol is a generic non-opioid painkiller. It is also used to reduce high fevers. It is available OTC as tablets, capsules, syrups, granules, and suppositories. It can be given via IV in a hospital setting.

Pregablin: Pregablin is a generic gabapentinoid medication used to treat epilepsy, anxiety and nerve pain. It is similar to gabapentin. It is available on prescription only as tablets, capsules, or a liquid.

Tramadol: Tramadol is a generic, high strength opioid painkiller. It is available on prescription in either tablet, capsule, or liquid drop form.

DECLARATION

I declare that this thesis is my own work and that, to the best of my knowledge and belief, it contains no material previously published or written by another person, except where due acknowledgement had been made in the text. I confirm that no part of the material presented in this thesis has previously been submitted by me or any other person for a degree in their or any other institution.

STATEMENT OF COPYRIGHT

The copyright of this thesis rests with the author. No quotation from it should be published without the author's prior written consent and information derived from it should be acknowledged.

ACKNOWLEDGEMENTS

I have been saving writing these acknowledgements as a ‘treat’, which should tell the reader something about my mindset as I edge ever-closer towards the PhD finish line. I have so many people to thank on this page, and I have been looking forward to doing so very much indeed – this thesis was a collaborative endeavour from start to finish.

Firstly, I would like to thank my supervisors Prof. Kate Hampshire and Dr Paul Chazot for supporting me throughout this project. Kate has been a source of academic inspiration for me since I was an undergrad, and since then has constantly pushed me to be the best anthropologist I can be. She has also taught me some very basic English grammar rules, for which I will forever be indebted. Paul has shown me what a truly interdisciplinary academic looks like – we should all take notes.

Thank you also to NINE DTP for funding this project in its entirety.

This thesis would not exist without all those who generously offered their participation in my research (our research). Thank you from the bottom of my heart. I hope I have done your experiences justice.

Doing my PhD at Durham during the pandemic was at times a very isolating experience. Nonetheless, a wonderful community pushed its way out of the ashes. Thank you to Chimwemwe Phiri, Ana-Maria Cîrstea, Halima Akhter, Akshita Mathur, Shivani Daxini, Johanna Thren, Andrea Lambell, Dr Alice Keegan, Katie Tobin, Dr Catrin Noone and Rachel Clamp for being fantastic friends and formidable academics, too. Thank you also to members of WAAD and the wider PGR community for feedback on previous iterations of some of the chapters in this thesis.

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Finally, and practically, I want to thank the crack team of proof readers who each took on a chunk of this thesis and spotted (most of, hopefully) the grammar and spelling errors. Thank you to James Chetwood, Julie Heald, Ana-Maria Cîrstea (again!), Akshita Mathur (again!), Nellie Saunby (again!) and of course my editor-in-chief, Tarandeep Sandhar.

James, I could not have written this without you. Thank you.

To James Heald, and to everyone else living in crip time.

1 Chapter One: Introduction and Methods

1.1 Introduction

I met Thelma[1] *and her two girls for a day out at Beamish, a local attraction catchily known as 'the living museum of the North'. By this time I had known Thelma and her two children – Georgina (6) and Bethany (8) – for a few months. Over the summer of 2021, we met up often. This was to pass the time and entertain the girls during the school summer holidays, which ran from mid-July to the end of August. Beamish is a popular local outdoor museum frequented by families – it uses interactive exhibits to chronicle the industrial histories of North East England, spanning from the Victorian era until the 1950s.*

I was excited to visit. I hadn't been before, despite the fact I only lived about 20 minutes drive away. I arrived a few minutes early, and wandered down towards the entrance, choosing to sit outside an old mining cart which served as a kind of landmark outside the entrance, in order to make myself obvious. I thought it would be warm, so was wearing t-shirt and summer trousers, with a shirt stashed in my rucksack in case the weather turned. There was a slight autumnal chill in the air which signalled the beginning of the end of summer, even though it was only the start of August. I decided to take notes on my phone throughout the day, as we would be walking around and I didn't want to distract the girls with my incessant note taking.

The number 8 bus pulled up to where I was sitting. It was predictably late, and the suspension lowered as the bus groaned to a halt. The driver got out to draw out the wheelchair ramp, to allow Thelma to disembark safely, and Thelma and the girls got off. They were all wearing sunflower lanyards, to inform others around them of their respective disabilities, and the girls were in matching unicorn patterned dresses. Bethany had on a pair of purple Doc Martens boots, which I complimented enthusiastically. Georgina had on a pair of wellies despite it not having rained for weeks. I learned later they were from 'Diggerland', a theme park they had visited earlier in the week on another summer holiday excursion. I waved at them and we greeted each other. I felt a little nervous as I had only spent an extended period of time with the girls once before, in their home. Thelma had said they sometimes felt uncomfortable around new people in strange places, partially due to the various learning disabilities they had been diagnosed with. However, Bethany, the oldest, immediately grabbed my hand to show me around Beamish, realising that I hadn't visited before and needed a guide. We moved down the slope towards the entrance of the museum and queued up to get in. We got to the front of the queue and Thelma sorted the tickets, which we had got for free as she and I were classed as carers for the children.

After getting the tickets, we walked through a door – Thelma called it the 'time portal' – telling the girls we were travelling all the way back to the 'olden times'. We emerged in a new world. Thelma asked the girls where they wanted to go first, and I soon realised that the primary aim for Bethany and Georgina was to get a plate of chips as soon as possible. So we went on our way, naming trees as a distraction as we made a beeline for the chip shop. Bethany was still holding my hand, which made taking notes impossible even on a phone. So, we spent our energy naming all the different trees we could see instead. The favourite of the day was the monkey puzzle tree, which stood at the bottom of the hill that led into the main part of the museum. As we walked, we all

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[1] All pseudonyms

discussed at length whether we thought a monkey would actually be able to climb it, or if it would get too confused.

Figure 1: An old mining cart, entrance to Beamish, Summer 2021

Finally, the chip shop emerged on the horizon. There was a queue, so Bethany and I walked up to the blackboard to check that the chips were vegan (both girls have an allergy to lactose, and Thelma does not eat animal products). It was then that disaster struck! The chips were cooked in beef dripping. We returned to relay the bad news. I felt disappointed too, as I was already hungry and was silently cursing myself for not eating a later breakfast to see me through the morning. We decided, instead of chips, to go and look at the old school and try and get some food later from the old tearoom nearby.

We moved on towards the school. I was conscious of how rough the terrain was, and how much Thelma's wheelchair was shaking over the gravel. When we got to the school, we realised a lot of it was shut off, and there was an obscure one-way system implemented due to Covid-19, that made it even less accessible. I could see Thelma was sore after moving across the gravel. We stopped to sanitise our hands and then decided to go and have a look at the farm, instead of trying to navigate a space that Thelma's wheelchair would not be able to fit in. This was up a rather steep hill, and I became increasingly aware just how much of Beamish was set on rough, uneven terrain. It struck me as quite unfair that the whole place could be made Covid-19 safe, but the provision for accessibility for wheelchair users and others with mobility issues was quite limited. Neither hand sanitiser nor wheelchair ramps are necessarily authentic to the 'olden times', but one had certainly been prioritised. We got to the farm and saw some ugly geese, turkeys, pigs, and plenty of chickens. Bethany was running around chasing them and squawking, while Georgina rode on her mum's knee. Thelma explained to me that her children were already beginning to experience their own forms of long-term pain, and how she was aware of their needs for rests from walking.

For the rest of the morning we explored the various exhibits Beamish had to offer. We visited the fairground – the events at which will be described at length towards the end of this thesis. We hunted around for suitable food to little avail. Towards the end of our visit, we made our way down to the old town in search of the old sweet shop that the girls had been telling me about all day. I was really hungry at this point. As the sweetshop came into view, we saw there was huge queue, which ran from the shop door down another step to the cobbled road. Thelma also gently pointed out to me that the one-way system meant that the only entrance was now completely inaccessible to her, as it was blocked by two steps.

What happened next was a very hostile encounter. We reached the sweetshop, Thelma in her wheelchair and her two children in sunflower lanyards running around and talking with increasing excitement about sugar mice. Thelma calmly and politely asked the man at the door of the shop, who was supervising the numbers inside in order to adhere to Covid-19 restrictions, to allow her and the girls to enter via the wheelchair accessible back entrance. The way he treated her was appalling. He looked down at her and said 'well, you'll have to queue up like everyone else... and then we will see what we can do about the entrance'. The disdain with which he spoke to her was shocking. Thelma, as always, remained calm and simply asked the man on the door how she was supposed to access the queue, as there was no dropped curb to allow her to safely get down onto the road. He simply shrugged and said that was not his problem. We both looked at each other, shocked, and unanimously decided the sweet shop wasn't going to happen. The girls were heartbroken.

We made our way to a little stall further down the street which looked like it sold sweets. We acquired a packet of blue raspberry lollies and decided to pop into the old bank next to the stall. While in the bank, Bethany dropped the lollies accidentally and smashed them all, so we went back a second time, much to the amusement of the man on the till. By the sweet stall there was a trailer full of teddies that blocked up most of the pavement, which again made navigating the road in a wheelchair impossible. I found myself piping up 'excuse me please' and trying to get people to move out of the way, or at least act with some form of awareness about the fact a mum in a wheelchair with two children was trying to get past. We all took a lolly and decided to keep walking around the site. It was later in the day now, and the sun had properly gone in. As we were walking, Thelma shivered and told me 'allodynia [pain due to a stimulus that does not normally provoke pain] and the breeze don't mix – it feels like shards of glass being passed over me'.

We entered a small play area, and Georgina immediately threw up blue froth. She had choked a little bit on her lolly, bringing up what she had managed to eat so far. Thelma cleaned her up sharpish, but Georgina started to cry, and said she wanted to go home. We were all getting tired and decided to walk back via the woods. As we headed towards the trees Bethany was walking in front of me, and I had my hands on her shoulders so that we could pretend to be a caterpillar going into the woods. Georgina was on Thelma's knee again, exhausted by the events of the day and unable to join in the game.

As we entered the woods Thelma was wincing. I made the mistake of asking what the pain felt like, and she said, with patience, 'please don't make me focus on it right now!'. We sat on a bench for a while, the girls running around, occasionally requesting for me to make an owl noise to entertain them. As they played, Thelma and I chatted for a while. Then, another crisis moment struck. Bethany needed the toilet. She went up to Thelma, looking upset, and said 'when people need to go to the toilet in the woods, how do they do it?'.

We had to go, right then. It was an emergency. Bethany was distraught and Thelma pinkie promised both the girls we could go straight back to the woods after the toilet, and keep playing. We moved at pace, Thelma's wheelchair going much faster than I could walk. Georgina and I ran behind, her pretending to be a squirrel and me an owl to keep her occupied, and to make the toilet break less frustrating for her. It felt like forever to get the toilet. When we finally arrived, the disabled toilet was occupied, so I ended up taking Bethany to the toilet while Thelma stayed with Georgina, as she couldn't access the ladies. As we came out of the toilet, Georgina was upset again. She needed to go now. Bethany and I waited outside while Thelma took her to the disabled toilet. After that, everything was calm.

We went back to the woods, a wasp chasing us. In the woods we played tag, and zombies, and Bethany and Georgina showed me what it was like in the Stone Age, while Thelma watched from afar, resting. We sat on the bench to drink a little water, and then decided it was probably time to head home. As we walked towards the gift shop, I could smell fish and chips and became aware how long it had been since I had eaten. In the gift shop I bought the girls another lolly each, which I gave to Thelma outside secretly, specifying they were for emergency use only! As we left Beamish, we found a bee struggling on the ground, and gave it some water in the hope we could revive it. Saving thirsty bees, and living in pretend worlds with Thelma's children became hallmarks of my fieldwork experience as the summer progressed.

As I drove home down the motorway, I could see rain streaking across County Durham, the clouds forming shadows across the landscape. I felt exhausted, but also like I had really gained some insight into Thelma's life. I kept thinking back to the way Thelma had been treated when simply trying to visit a sweetshop with her children, and felt extremely sad that life for her always had limits placed on it by the outside world.

The above scene depicts events characteristic of how life is spent 'living under' (Martin, 2007) a diagnosis of chronic pain in North East England. Chronic pain is not just an uncomfortable sensation, but is a disabling, chronic illness that touches every aspect of life (Bury, 1982; Good *et al.*, 1992; Jackson, 2000). This thesis focuses on the impact living with chronic pain has on how a person experiences and moves through time. Pain, as described by Scarry (1985), is 'the making and unmaking of the world'. Through this making and unmaking, time becomes warped; past, present and future merge, interact and play out in unsuspecting ways. My experiences with Bethany, Georgina and Thelma demonstrate much of the essence of what it is like to navigate through time while living with long term pain. A person must constantly plan around challenges, while trying to wrangle the needs and urgencies of the present into submission. All the while, the shadow of the North East's industrial past shapes how health and illness play out in this part of England.

This doctoral thesis emerges from approximately 14 months of ethnographic fieldwork, conducted via the internet and in person between October 2020 and December 2021. It is centred around the lives of people, almost exclusively women, who live under a diagnosis of chronic pain in North East England. I had been living, working and studying in and around the North East for years before 'entering' the field, and well after my defined fieldwork period had ended. Many of the insights in this thesis are therefore borne out of something much longer than a defined, and ethically sanctioned, "fieldwork" period.

Importantly, this research took place throughout the Covid-19 pandemic. As such, the conditions I was working in radically changed the aims and outcomes of my research. Originally, I intended to explore the use of prescription opioids to manage chronic pain in the North East, but my plans changed due to the practical limitations the pandemic placed upon my ability to do research. However, alongside the vast waves of acute infections characteristic of the years 2020 and 2021, Covid-19 has also impacted the way chronic illnesses are perceived in the public psyche, through the cases of 'Long COVID' which can occur after acute infection. Consequently, the research questions I was concerned with changed too. In this thesis, I explore the following questions:

- What is everyday life like for people who live with chronic pain? How does living under a diagnosis of chronic pain in the everyday alter a person's relationship to time?
- What social relations exist between chronically ill people? What is the role of 'support groups' in managing chronic pain?
- What social relations exist between chronically ill people and, their doctors, and the state?
- How are broader inequalities embedded in the chronic pain landscapes of North East England? How do these inequalities play out in people's lives?

In this introductory chapter, I first provide some background to doing research in the North East, situating it in the wider historical and social context, and providing a brief overview of the British welfare state. After this, I outline the methodological and ethical choices I made to allow me to continue doing research in the middle of a pandemic. Finally, I provide an overview of the research participants and groups important to this thesis, alongside a chapter-by-chapter summary of what follows.

1.2 Background: Chronic pain and socio-economic disadvantage in NE England

1.2.1 An introduction to North East England: Historical and socio-economic context

There is not space in this thesis to provide a full overview of the complex history that has shaped North East England. Here, I provide a very brief overview of important context for the reader to know and understand. North East England can be seen to serve as a 'frontier zone', bordering Scotland to the north and Yorkshire to the south (Jackson, 2019). Crucially, The North East was 'one of the birthplaces of industrial capitalism' - in the nineteenth century, it saw huge growth centred around the extraction and production of coal, iron, steel and chemical industries (Hudson, 2005: 82). As a result, communities in the area became dependent on these industries for their livelihoods, and economic activity became concentrated around the production of coal and steel (Beynon, Hudson and Sadler, 1986; Fowler, Robinson and Boniface, 2001). In the latter quarter of the twentieth century, rapid deindustrialisation occurred in line with the neoliberal economic policies of Margaret Thatcher's government. This deindustrialisation culminated in the Miner's Strikes of 1984-1985, and the social upheaval which occurred thereafter (Scott-Samuel *et al.*, 2014; Forster, Petrie and Crowther, 2018). Arguably, after this, large parts of the North East became a marginal 'industrial wasteland' (Hudson, 1986: 170).

Presently, the North East has a population of approximately 2.6 million people, the smallest population of any region of England. It is also the least ethnically diverse part of the country – 90.6% of the population are white (Office for National Statistics, 2023). As of 2022, unemployment in the North East stood at 4.8%, 1.3% above the England average (North East Evidence Hub, 2023). Furthermore, a person who lives in the North East and is employed is more likely to be low paid than if they are working almost anywhere else in the UK (Office for National Statistics, 2022).

Nationally, there are huge differences in life expectancy between the North East and the rest of England. A baby boy born in the North East between 2018-2020 has a life expectancy of 77.6 years (the lowest in the country), while a baby girl born at the same time can expect to live 81.5 years (Office for National Statistics, 2021a). This is compared to a national average life expectancy of 79.0 years for boys and 82.9 years for girls (Office for National Statistics, 2021b). These trends in life expectancy suggest a worsening pattern of health inequality in the North East versus the rest of England (Bambra, Barr and Milne, 2014; Corris *et al.*, 2020).

Similarly, there are enormous inequalities within the North East region itself. The *'Health Inequalities in an Age of Austerity: the Stockton-on-Tees Study'* examined these local health inequalities in detail, using both ethnographic and statistical methods (for examples see: Garthwaite and Bambra, 2017; Akhter *et al.*, 2018; Langthorne and Bambra, 2020; Akhter *et al.,* 2021). This research, undertaken in a coastal town in the North East, emphasises the stark differences in life expectancy (a 17.3 year gap for men, and an 11.4 year gap for women) between the most and least deprived individuals in the region, alongside concerning trends in many other important health inequalities metrics (Garthwaite and Bambra, 2017: 270).

These historic and demographic factors provide a snapshot of the North East; it was previously one of the industrial powerhouses of England, it has a low population, it is ethnically homogenous, it has higher-than-average unemployment and lower-than-average pay, and it has a relatively low life expectancy. As a consequence, certain areas of the North East are often referred to as being 'left behind'[2] parts of England (Oxford Consultants for Social Inclusion, 2019). These 'left behind' neighbourhoods are disproportionately situated in the post-industrial areas of northern England and have markedly poorer social infrastructure. Much of my fieldwork was carried out in these 'left behind' neighbourhoods, and in this thesis I look specifically at the impact they have on health.

1.2.2 The 'Pain Divide' and health inequalities

The reasons for choosing North-East England as my field site were based on the historic and socio-economic context above, alongside identified problems with chronic pain prevalence and opioid prescriptions in the area. North-East England has the highest prevalence of chronic pain, alongside the highest number of opioid prescriptions per capita in the country (Mordecai *et al.*, 2018; Todd *et al.*, 2018; Alenezi, Yahyouche and Paudyal, 2021). Todd *et al.*, (2018) observe a north-south 'pain divide' with people living in northern England – including the North-East – significantly more likely to have chronic pain and be taking opioids than in the south of the country, thus providing one example of how health in England can be mapped geographically. Superimposed on this north-south divide is variation in numbers of opioid prescriptions, which are themselves associated with rurality and index of deprivation (Mordecai *et al.*, 2018; Curtis *et al.*, 2019). Therefore, regional differences in opioid prescriptions need to be considered and contextualized within the wider context of north-south health and socioeconomic inequalities (Todd *et al.*, 2018)

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[2] There is a debate, which I have avoided getting into here, about whether 'left behind' is simply used as shorthand for 'white working class', ignoring other aspects of inequality (Wallace and Favell, 2023)

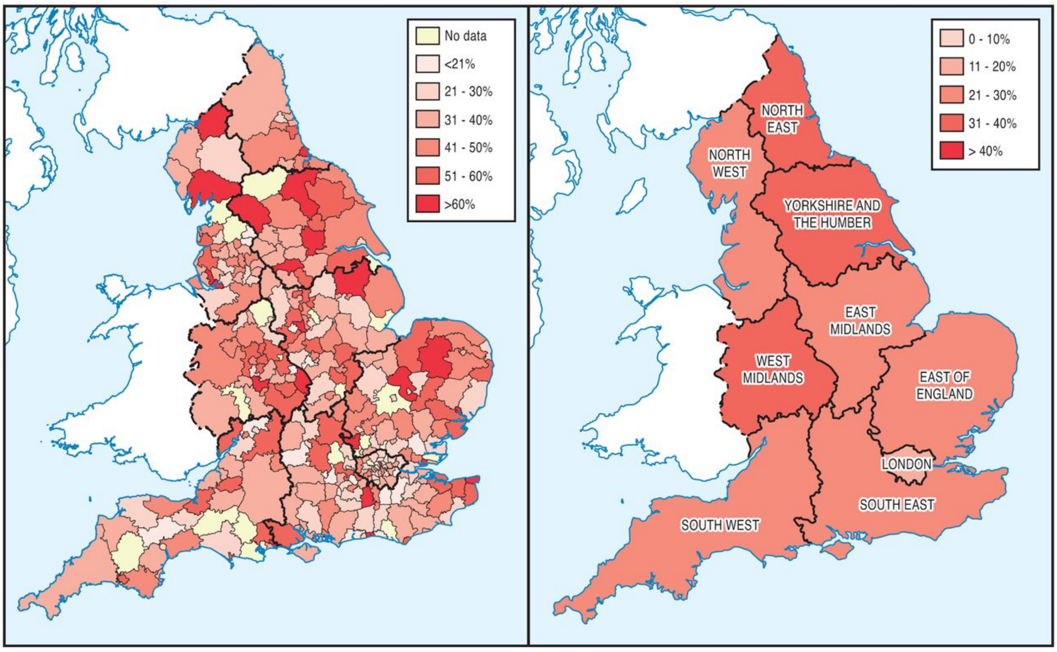

Figure 2: A map showing the 'pain divide' present in England. Areas in darker red indicate a higher prevalence of pain (Todd et al., 2018).

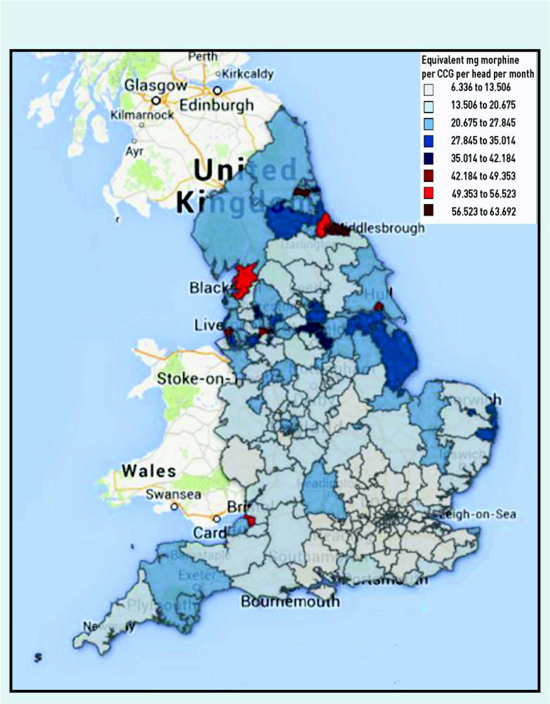

Figure 3: A map showing equivalent mg morphine prescriptions per CCG (clinical commissioning group) per head per month, in England (Mordecai et al., 2017). The North East, and parts of the North West, show high amounts of opioid prescriptions.

Alongside these identified problems with pain and opioid prescriptions are broader issues of health inequality. Marmot (2020a) has described these issues in depth. Fundamentally, North East England is demonstrative of an ever-increasing divide that exists between different socio-economic groups in England. This *recent* increase in inequality can be traced back to the impact of the austerity policies implemented by the coalition government in the aftermath of the 2008 recession, and the policies of the New Labour government before that (Shaw, Smith and Dorling, 2005; Dorling, 2010; Clifton *et al.*, 2013; Stuckler and Basu, 2014; Bambra and Garthwaite, 2015;

Clayton, Donovan and Merchant, 2016; Ballas, Dorling and Hennig, 2017). For example, Marmot (2020a) emphasises that for the most deprived 10% of women in North East England, life expectancy has lowered in the last 10 years. Evidence also suggests that these policies have disproportionately impacted marginalised groups, for example women (Raynor, 2021) and refugees (Flug and Hussein, 2019). The long-term impacts of austerity policies are now being seen via negative effects on both physical and mental health within populations located in the North East, and as such the area has been subject to large amounts of research into health inequity in the UK (Bambra, Barr and Milne, 2014; Bambra and Garthwaite, 2015; Garthwaite, Collins and Bambra, 2015; Smith, Bambra and Hill, 2015; Mattheys *et al.*, 2016; Akhter *et al.*, 2018; Corris *et al.*, 2020).

It is important here to note that these trends are complex, and are not just limited to the North East. Inequalities in life expectancy exist within urban areas like London, and also between rural and urban areas of the UK (Dorling *et al.*, 2000; Bennett *et al.*, 2015; Marmot, 2020b). However, the types of inequalities observed in North East England are the ones of special importance to this thesis: increasing rates of chronic illness, pain, multi-morbidity and unemployment (Mercer *et al.*, 2012; Marmot, 2020a). Furthermore, anthropologists have demonstrated the utility of ethnographic methods when examining the links between deprivation, the over-prescription of certain pharmaceuticals and the presence of multi-morbidity in certain deprived populations in the UK (Ecks, 2021). As such, exploring the issues outlined above using these methods is important when trying to understand the manifestation of these inequalities on the ground.

1.2.3 The British welfare state

A report by the Institute for Public Policy Research (IPPR), released in December 2022, found that 8.4% of people in North East England were 'economically inactive' due to ill health (Thomas, 2022). This is the third highest percentage in the UK, after Northern Ireland and Wales, and the highest percentage within England. The ability to access social security in these areas is integral to understanding further what it is to live with chronic illness or disability in North East England. Alongside an understanding of the broader health inequalities that shape the North East, the links between deprivation, poor health and unemployment need to be contextualised with an understanding of what the British welfare state is, and how it works.

For the women who took part in my research, access to benefits (or lack thereof) was something that hugely impacted their lives. The reason for this is twofold. Primarily, being chronically ill can limit a person's ability to work, and therefore access to the welfare state can make the difference between living in relative comfort or living in poverty. Secondly, and less tangibly, being granted state welfare benefits can allow a person to evidence that they are 'really' ill and can allow access to other forms of disability support such as Blue Badges, travel passes and Carer's Allowances. This second theme will be discussed at length throughout this thesis. Here, I provide some background to the British welfare state, and some of the bureaucracies people must navigate in order to access material support for their illnesses.

The origins of the British welfare state lie in the aftermath of World War II. Its aim was to provide a system of social insurance 'from the cradle to the grave'. One part of this package of support was the provision of social security 'benefits' to support those who were unemployed or unable to work (Briggs, 1961; Renwick, 2017). Today, the administration of these benefits is overseen by the DWP (Department for Work and Pensions). To obtain benefits, especially if seeking incapacity benefits, certain thresholds for eligibility must be reached. In recent years, the DWP has come under much criticism for its punitive approach to incapacity benefits. Numerous headlines have detailed the treatment people have experienced while applying for benefits, including patients with terminal cancer being denied access to state funds and being declared 'fit for work'. Recent academic research has raised concerns about the appropriateness of the current system, specifying detrimental effects on claimants' mental and physical health as a direct consequence of the welfare state as it stands (Bambra and Garthwaite, 2015; Cheetham *et al.*, 2019; Bambra and Lynch, 2020; Wickham *et al.*, 2020). Similarly, alliances between academics and activists, such as can be seen in the 'Deaths By Welfare' project have been investigating deaths linked to welfare reform in the UK (Healing Justice London, 2023).

Practically, there are two main categories of sickness benefits. Firstly, there is the category previously known as ESA (Employment Sickness Allowance) which now falls under the umbrella of UC (Universal Credit). UC also encompasses JSA (Job Seekers Allowance), which is the benefit awarded to people while they are actively seeking work. UC is a means tested benefit, meaning that a person needs to have an income under a certain threshold, and have under £6,000 in savings in their bank account to be eligible. At the time of writing, some of my participants still receive ESA, now known as a 'legacy benefit'. The eventual aim of the DWP is for all means tested benefits recipients to be on UC, to streamline the process and make it less bureaucratic. Being granted access to sickness benefits while on UC means that the state has declared that you are 'too sick' to be able to work more than 16 hours per week. As such, these benefits are meant to replace income which would otherwise come from full-time employment, either on a temporary or permanent basis.

Secondly, and most pertinent to this thesis, is the provision of Personal Independence Payment (PIP). PIP is intended to provide support for people living with long term illnesses or disabilities, without removing a person's right to work full time. PIP is described by the UK government as follows:

> Personal Independence Payment (PIP) can help with extra living costs if you have both:
> a long-term physical or mental health condition or disability
> difficulty doing certain everyday tasks or getting around because of your condition
> You can get PIP even if you're working, have savings or are getting most other benefits.
> (UK GOV, 2023)

Importantly, access to PIP is facilitated via an assessment process. To obtain PIP, several forms detailing the impact of a person's condition(s) must be filled in and submitted to the relevant administrator. From there, applicants are subject to a physical examination and interview by a 'healthcare professional'[3] to determine their eligibility for the benefit. During periods of Covid-19 lockdown, these assessments took place over the telephone. Questions are focused on the activities of daily life; whether a claimant can cook for themselves, put their coat on unaided and walk across the room without any mobility aids. Total scores are awarded in two domains – 'daily life' and 'mobility'. Claimants are awarded points dependent on how severe their impairment in each 'activity area' is. To be eligible for PIP, a person must score over a certain number of points throughout the assessment process.

For my participants, interactions with the British welfare state were deeply woven into other life experiences. The implications of living in a society which quantifies illness using a points-based metric has far reaching

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[3] This could be a physiotherapist, nurse, paramedic, or occupational therapist. There is no guarantee the medical professional will have any expertise in your specific conditions.

consequences for how my participants viewed themselves and their illnesses. These implications are diffused throughout this thesis. Living under a diagnosis of chronic pain in the North East involves a constant fight for resources; through access to medicines or other forms of healthcare, to financial support and to social support. The spectre of 'deserving' sickness overshadows how people view themselves and plan their futures.

1.3 Methods: Doing an ethnography of chronic illness in a pandemic

1.3.1 Pandemic methodologies

The original aim of my PhD was to understand how opioids are used for chronic pain in the aforementioned 'left behind' areas of North-East England. I wanted to understand how opioids were circulated, used and understood by those living under a diagnosis of chronic pain. To do this, I was hoping to draw from methodologies within the anthropology of pharmaceuticals. I planned to work from the premise that these pharmaceuticals had 'biographies' (Geest, Whyte and Hardon, 1996) and 'social lives' (Whyte, Geest and Hardon, 2002) which could be traced as they moved from place to place. By using the opioid as a 'tracer tool' (Sismondo and Greene, 2015:2) I hoped to 'follow the molecules'(Ecks and Harper, 2013: 256) that constituted these painkillers, as they moved from the point of prescription to the point of ingestion and (hopefully) efficacy. To do this, I intended to apply for NHS (National Health Service) ethics permissions and to recruit participants from a general practice (GP) clinic in the North East.

As I began to apply for NHS ethics clearance in February 2020, amid rapidly rising cases of the Covid-19 virus in the UK, I began to realise that this plan might not come to fruition at all. In mid-February 2020, I was working on campus and took a break to go to the toilet. As I washed my hands, I read one of the many posters which had been hastily plastered on the bathroom wall. It warned that any person who had returned from China in the last 14 days and had developed a fever or persistent cough should quarantine immediately and inform Public Health England. It was at this point I realised the true severity of the pandemic, and began to reconsider my fieldwork plans.

On the 23rd March 2020, a national lockdown was declared by the then Prime Minister, Boris Johnson. Those not in 'key worker' roles were mandated to stay at home, aside from once-daily exercise and shopping for essential items. This had an immediate impact on PhD students and other researchers, who were not classed as key workers. In an email from the 23rd March 2020, the following advice was communicated through email via my DTP (doctoral training partnership):

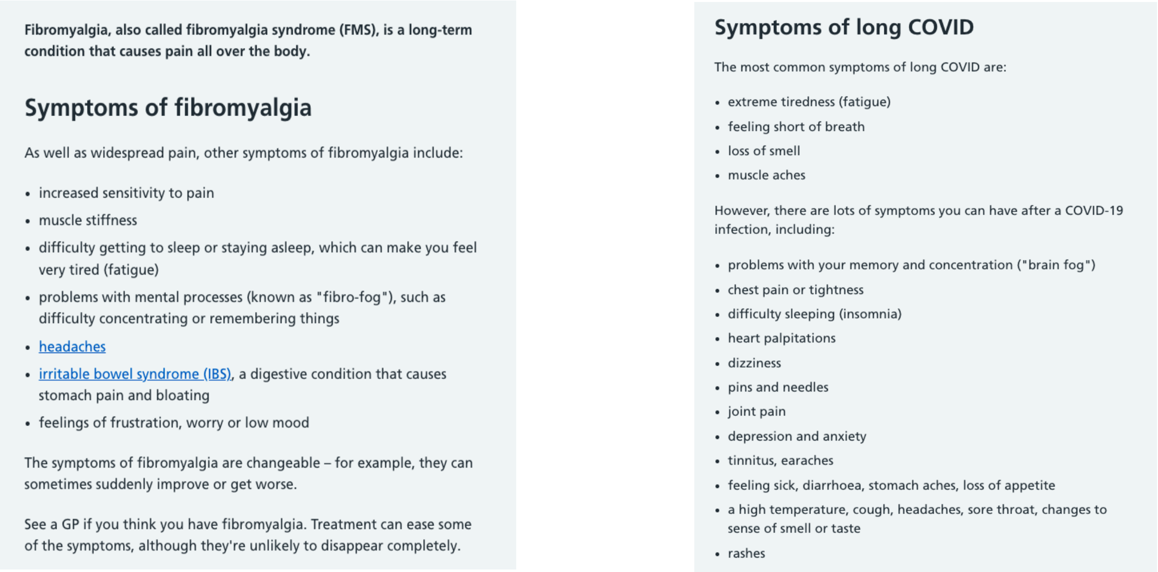
> 'For those of you still with research to conduct, we encourage all our DTP students to discuss with their supervisors two sets of potential plans – (a) for a four-month delay, assuming they can resume fieldwork thereafter, (b) for longer term disruption. We do not think you should rush decision making around this, or start new work, but be exploring possibilities for what direction you might need to go in.'

Further advice from UK Research and Innovation (UKRI) stated that students who still needed to undertake fieldwork should 'adapt and adjust' their research projects to ensure that work could still be carried out within the funded timeframe (UK Research and Innovation, 2020). The implications of all of this were that research planned to be carried out face-to-face should be shifted online for the foreseeable future.

For the first few months of lockdown, many stressors meant that continuing with research (and indeed life) as normal was impossible. One important caveat is that my experiences doing fieldwork at a time of immense global crisis are but one example of the broader social, mental and physical challenges faced by the world's population during this time. During those first few months, prioritising health and avoiding infection were paramount, and research came second. Throughout the years of the pandemic I have found myself, alongside others in my cohort, worrying that the research we were producing was not going to be enough, or was going to fail the groups of participants we had spent years planning to work with.

As I write and reflect on this now, in 2023, it is clear that what we did was more than enough. Getting through the pandemic with any data and my mental and physical health (mostly) intact was achievement enough in itself. There were others in my circle of friends and colleagues who were less lucky. This methodology should be read in light of this – often the choices I made were a result of needing to make quick and flexible decisions which would not place my participants, or myself, at risk of infection. However, I feel many things can be learned from the way this research was carried out. In what follows, I describe how my research was conducted, and consider what the ethical implications of the practical changes I needed to make made to my research designs.

Very importantly, doing a PhD about chronic illness at a time of mass viral infection also changed the epistemology of chronic illness within which I was working. Alongside acute infections, reports of cases of post-infection 'Long COVID' began to emerge. The majority of the women who took part in my research had a diagnosis of a condition called 'fibromyalgia', often colloquially referred to as 'fibro'. Interestingly, the symptoms of this condition are almost identical to those ascribed to Long COVID. Throughout fieldwork, multiple participants stated to me how unfair it was that it was *'only due to covid'* that people had begun to care about chronic illness. They expressed resentment that those with Long COVID were able to access specialist support, while they were left with nothing. The symptom profiles of both fibromyalgia and Long COVID, as described by the NHS, are shown below (Fig. 4).



Fibromyalgia, also called fibromyalgia syndrome (FMS), is a long-term condition that causes pain all over the body.

Symptoms of fibromyalgia

As well as widespread pain, other symptoms of fibromyalgia include:

- increased sensitivity to pain
- muscle stiffness
- difficulty getting to sleep or staying asleep, which can make you feel very tired (fatigue)
- problems with mental processes (known as "fibro-fog"), such as difficulty concentrating or remembering things
- headaches
- irritable bowel syndrome (IBS), a digestive condition that causes stomach pain and bloating
- feelings of frustration, worry or low mood

The symptoms of fibromyalgia are changeable – for example, they can sometimes suddenly improve or get worse.

See a GP if you think you have fibromyalgia. Treatment can ease some of the symptoms, although they're unlikely to disappear completely.

Symptoms of long COVID

The most common symptoms of long COVID are:

- extreme tiredness (fatigue)
- feeling short of breath
- loss of smell
- muscle aches

However, there are lots of symptoms you can have after a COVID-19 infection, including:

- problems with your memory and concentration ("brain fog")
- chest pain or tightness
- difficulty sleeping (insomnia)
- heart palpitations
- dizziness
- pins and needles
- joint pain
- depression and anxiety
- tinnitus, earaches
- feeling sick, diarrhoea, stomach aches, loss of appetite
- a high temperature, cough, headaches, sore throat, changes to sense of smell or taste
- rashes

Figure 4: NHS overview of fibromyalgia (left) vs NHS overview of Long COVID (right) (NHS, 2023b, 2023a)

As I navigated through my PhD during the pandemic, I found that I was working at a time of increasing focus on chronic illnesses. As a result, my PhD switched from focusing on how the molecules that make up different painkillers move, to the embodied experience of being chronically ill. For my participants, the fact the NHS was willing to put on special clinics for those impacted by Long COVID further evidenced the lack of support for those already living with non-Covid-related chronic illness. Of course, the patterns of provision of Long COVID services are limited in a way that very much mimics the provision of health services in the UK more broadly (Sivan, Rayner and Delaney, 2021). However, this emphasis on Long COVID and the feelings of injustice experienced by my participants began to facilitate my switch to thinking about what the day-to-day injustices that surround life with chronic pain are actually like.

1.3.2 Accessing participants and collecting data

When the shock of the pandemic began to fade slightly, I needed to make plans to allow me to do whatever fieldwork I could salvage. I decided, due to prior experience doing research using social media, to try and recruit participants via local chronic pain support groups on Facebook. I spent several hours trawling the internet and typing in different combinations of 'area in North East England' + 'chronic pain'. I found several groups that looked promising. I requested to join them using my personal Facebook account[4]. Following acceptance, I sent the administrator of each group a message introducing myself and asking if it would be okay to post my research materials in the group. Once I received permission to do so, I posted my recruitment materials in the group, and asked anyone who would be interested in finding out more about my research to either comment on the post, or message me directly.

After I made contact with interested parties, I spoke to them using Facebook's instant messaging function and asked to take their email address (if they had one) to allow me to send them some more information from my official Durham email account. From there, I sent another copy of my information sheet, alongside some information about myself and what taking part in the research might entail. If the person replied with interest, we arranged a call (normally via Zoom, but sometimes over the telephone or via Facebook's video call function) to talk through the consent process and get to know each other.

I came, in my head, to think of these calls as 'consent calls'. After getting over the awkwardness of talking to a stranger via video call, I would go over why I had chosen *not* to ask for signed consent to take part in the project. I emphasised that participation or non-participation was completely voluntary and could be withdrawn at any time. I also made it clear that I would ask about consent at multiple times during the process, to ensure that the participant was comfortable to continue with the research. We also spoke about the possibility that some distressing memories or feelings might come up as part of the research process. Making sure the participant was okay to talk about these things, and knew they could stop if it ever got too much, was a central part of the consent call. Most importantly, I emphasised to participants that they should not talk to me about anything they did not want to, or did not feel comfortable with. I took consent from 17 people in this manner, and went on to interview all of them. Of these 17, I spoke to 12 more than once, some being recorded interviews and other being more informal 'online hangouts'.

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[4] I did not make a research specific Facebook account as I wanted potential participants to see I was a real person. I changed my security settings so that I could not be added as a friend, but invited potential participants to send me a direct message to find out more information.

The implications of the pandemic were especially present throughout the first six months or so of fieldwork. The 'consent calls', mentioned in the above paragraph, were all undertaken during periods of lockdown when meeting in person was illegal. As time progressed, and I got to know participants better, we discussed the possibilities of meeting up when restrictions lifted. Of the 17 people I spoke to over the lockdown period, I met up with 10 in person (some on multiple occasions) across the spring, summer and autumn of 2021. The remaining 7 were either too busy with work to meet up with me, did not want to take part in the research long term, or were still wary about infection with Covid-19 and chose to avoid meeting up in person for safety reasons. During these periods, I first went on walks with people when meeting indoors was still illegal, and then progressed to visiting people in their homes and doing other activities, if they felt comfortable with me doing so.

Later in 2021, after all legal restrictions lifted in the UK, I got in contact once again with the administrators of two Facebook groups I knew were beginning to meet up in person. The details of these groups will be provided later in this chapter. After seeking permission once again, I attended these groups in person from September-December 2021. On the first visit to these groups, I handed out paper copies of my information sheet, and asked for consent to take part from those present at the group. I asked anyone who had any questions or concerns to either speak to me individually or contact me via email or text, and found time to check in with every group member present at some point during the meeting. All members of the group were keen to take part, and often waved me away when I asked to double check how comfortable they were with taking part. I emphasised during these sessions that I would anonymise anything said during them, and change some details to ensure that members of the group were not identifiable.

I attended these groups on an ongoing weekly basis during the last few months of my fieldwork. If anyone I had not met before joined the group, I gave them a copy of my research information, asked for verbal consent and also contacted them by email if they requested, to see if they had any further questions. During the time I attended support groups, no participants declined to take part.

1.3.3 Data collection

As mentioned above, I interviewed every participant I spoke to via video call. These interviews were recorded with verbal consent, and some participants were recorded speaking multiple times. I did not interview any members of the support groups I visited on a one-to-one basis. There were a few reasons for this, one being that by this point in my fieldwork I was exhausted and more keen to explore the connections and friendships forged in these groups, rather than examining individual's (often very traumatic) personal histories and illness narratives. Instead, I attended these groups and participated in their activities, taking fieldnotes all the while. I took part in craft activities, curling competitions and even attended a traditional 'pie and pea supper' fundraiser put on by one of the groups, alongside other miscellaneous trips and events. I was interested in the support networks that emerged at the groups, and aimed to understand the function of them more broadly. Why did people attend them? What sort of things were talked about by people with a common illness or symptom profile?

Throughout the entire course of my fieldwork, I stayed connected with participants over text or WhatsApp, and also via email and Facebook. These chats occurred alongside meeting up for walks and home visits, and attending support group meetings. This is important, as texting proved useful even during the periods of fieldwork when there were no restrictions on socialising – part of the methodology I had developed in response to the pandemic became useful to me even when the impact of Covid-19 on my work began to fade.

In summary, as consequence of the pandemic, my data comes from two sources: the people I contacted via Facebook, and the people I met in person at the groups. Of course, in reality, all of the research I did stemmed from engagements with the internet. I would not have known that the in-person support groups existed without looking for them online. As a result, the use of online methods became an extremely important part of my methodology.

1.3.4 Reflections on online ethnography and disability studies

As noted above, the first few months of my fieldwork were spent entirely online. I had previously undertaken research using the social media platform Instagram, so I revisited the literature on online ethnography to aid me in carrying out this first part of my research project. I explored how social scientists have used these methods to understand how the internet shapes health and illness (for examples see: Gillett, 2003; Nettleton, Burrows and O'Malley, 2005; van Uden-Kraan *et al.*, 2008; Lowe *et al.*, 2009; Gonzalez-Polledo, 2016; Gonzalez-Polledo and Tarr, 2016; Marcus and Singer, 2017). This kind of research focuses on how the Internet is used by people with different health conditions to find information, interact with others with similar conditions, and create new meanings around illnesses. For my own project, I was less interested in how the internet is used to discuss health, and more focused on accessing research participants via online methods. Through writing a paper on this topic (Johnson, 2022), a reviewer urged me to consider the impact of disability studies on the use of online methods to study health.

The Internet has long been used by disabled scholars and activists to produce research, and to create and maintain activist communities. A prominent example of these interactions is Boellstorff (2008)'s ethnography *Coming of Age in Second Life: an Anthropologist Explores the Virtually Human* and subsequent articles (Boellstorff, Davis and Krueger, 2013; Boellstorff, 2019). Other examples, often from within (or drawing from) critical disability studies, have emphasised the importance of the Internet for disabled people both in terms of providing specific accessibility, and also the epistemic consequences of carrying out research online (for examples see: Ginsburg, 2012; Burke and Crow, 2016; Davis and Boellstorff, 2016; Hartblay, 2019).

By looking at these two distinct, but interlinked, bodies of literature, I began to consider what it meant to try and do an ethnography of chronic illness that was flexible and able to jump across, and in-between, online and offline spaces. When I thought about my data – what I had been doing, and what I wanted to do – I realised that doing research in this way allowed me to build different types of 'access' into my research design. By incorporating ideas from both online ethnography and disability studies, I was able to access different people, spaces and times throughout the course of my fieldwork (Johnson, 2022). These types of access often intersected, and allowed me some very interesting windows into the lives of my participants.

While talking to people online during lockdown, I realised that many participants might have been unwilling to speak to me had I tried to recruit them through their GP. This was because of negative experiences with clinicians in the past leading to distrust of the NHS. By recruiting using social media, I circumvented many of the strange power dynamics that link together chronically ill women and health systems. Similarly, by speaking to people using remote methods, like Zoom, I was able to chat with people when they were feeling unwell, or having a 'bad day'. By doing this research partially online, I was able to see some of the details and spaces of everyday life I may not have seen had I followed my original research plans. Finally, I used WhatsApp consistently throughout my fieldwork. Often, I would text participants to check in on them, or they would send me updates when they felt like they were experiencing something I would like to know about. Throughout this thesis, I use excerpts from texts as ethnographic data. Through texting, I was able to ensure that participants could contact me whenever suited them, and that they could participate in research in ways that extended beyond more traditional models of how fieldwork should be done.

Fundamentally, doing my PhD this way allowed me to increase its accessibility. Even when I visited the support groups face-to-face and met up with other participants during the second part of my time in the field, I maintained the principles and approaches detailed above. By using methodological approaches and epistemologies from both disability studies and the history of online ethnography, I was able to produce research which straddled the boundaries between online and offline worlds.

1.4 Ethics as influenced by Covid-19

> 'anthropology, if it is to be worth anything at all, must be ethically grounded'
> (Scheper-Hughes, 1995: 409)

In the above quote, Scheper-Hughes is writing about the role of the anthropologist in, and beyond, field research. She describes her own experiences while writing her famous ethnography *Death Without Weeping: The Violence of Everyday Life in Brazil* (Scheper-Hughes, 1992)*,* and contemplates the specific ethical responsibilities anthropologists have to those they work with. When studying pain and suffering, she argues that it is the anthropologist's role to write about these 'ills in a spirit of solidarity' (Scheper-Hughes, 1995: 419). In her view, the anthropologist exists as a witness who records 'partial records of human lives' (Ibid.). They are a *companheira* (companion), who cannot avoid involvement in the lives of participants. By doing so, ethnographies which are 'personally engaged and politically committed' (Scheper-Hughes, 1995: 419) can be produced.

The work I attempted to do during 2021 cannot be broadly separated from the wider landscape of health inequalities in North East England. The people I got to know during the periods of lockdown became my friends; we met during a time of particularly intense upheaval which inevitably led to discussions around access to healthcare and experiences of services in an area of high deprivation and low resource (both pre- and during Covid-19). Throughout my time in the field, I was aware of the fact that many of my participants had been subject to the 'epistemic injustice' those who live with invisible illnesses such as chronic pain are subject to (Fricker, 2009; Buchman and Ho, 2014; Carel and Kidd, 2014; Buchman, Ho and Illes, 2016; Buchman, Ho and Goldberg, 2017). Dumit (2006) describes these illnesses as 'illnesses you have to fight to get', placing emphasis on the difficulties many people (especially those who are marginalised) have seeking a diagnosis for long-term and/or rare conditions.

Because of this, I took the ethical position of belief and solidarity with my participants. When we began talking, I made it clear to any potential participants that they could speak to me and be assured that I believed their pain was real. I repeatedly emphasised that that they could tell me anything about their experiences of pain, and I would believe them. My ethical approach was formed from an explicitly feminist epistemology, focused on understanding the connections between people, and the social worlds around them which shape and produce knowledge (Grasswick, 2004). I describe this approach further in Chapter Two.

The ethical positions and approaches I took during my time in the field were inevitably influenced, and often driven, by the methodological choices I described earlier in this section. Doing my research partially online allowed me to engage with the 'disability anthropology' promoted by Hartblay (2020). By contacting people using flexible mediums I was, inadvertently, engaging with much of the literature around disability and the internet discussed above. In this sense, my research became more accessible and, by extension, more ethical. I was able to contact people in a way that worked for them, while being mindful of the limitations their disabilities sometimes presented. The types of 'access' I was able to produce demonstrate the ethical possibilities doing research in hybrid ways can present (Johnson, 2022).

However, my research was also ethically problematic. Evidence suggests that Covid-19 is a 'syndemic pandemic' (Bambra *et al.*, 2020). The idea of the 'syndemic' emerged from research done at the intersection of public health and critical medical anthropology, and describes the interaction between two or more 'afflictions' during an infectious disease outbreak (Singer and Clair, 2003). As Covid-19 has become more established in communities in the UK, rates of mortality and serious disease from the SARS-CoV-2 virus correlated with existing patterns of health inequality. In this sense, those most severely impacted by existing health inequalities are also those statistically most at risk of serious harm from Covid-19 infection. This included many of the women who took part in my research.

The shift to working online was ethically necessary, and was mandated by funding bodies and university ethics boards alike, in order to prevent harm to researchers and participants, for the reasons detailed above. However, health inequalities do not exist in a vacuum. In the same way that the pandemic has shone a spotlight on inequalities in health, it has also highlighted enormous inequities in Internet access, both in the UK and globally (Majeed, Maile and Coronini-Cronberg, 2020; Watts, 2020). These concerns regarding digital exclusion are not new. ONS data has shown that that UK has a persistent "digital divide" which hinges along axes such as age, ethnicity, socio-economic status and disability (Office for National Statistics, 2019).

The issue of digital inequality is therefore central when researching health inequalities during a pandemic (and beyond). For my own research, knowledge of this is especially pertinent. North East England has the highest proportion nationally of non-Internet users: 12.1%, of which disabled adults make up a disproportionate share (Office for National Statistics, 2019). From this, we can infer that people living under a diagnosis of chronic pain may be disproportionately excluded from Internet access, or lack the 'digital capital' (Hampshire *et al.*, 2015) that would allow them to participate in online research (or indeed, access online healthcare) with ease.

Doing online fieldwork on chronic pain in North East England therefore raised significant ethical questions about representation and exclusion. Who is not being represented when research is pushed online through necessity, rather than design? Did I risk systematically excluding people whose experiences are crucial to understanding the mechanisms of social inequality and exclusion by moving my research online? How could I produce work focused on the experience of chronic illness which places access at its very core, if those most likely to be impacted by what I was studying were unreachable? I do not have all the answers to these questions, but hope the experiences I have presented here allow some space to consider both the ethical benefits of doing research online, but also the potential ethical dilemmas. Even with an understanding of how disability studies have historically used the Internet to produce research and create activist spaces, it is still necessary to raise these questions in this thesis, and consider them while reading through the body of my ethnography.

Thinking about what the Internet can do, or might do, for health research has the potential to produce some wonderfully interesting and innovative research. My research methodology, although fractious and often reactive, produced some insights into people's lives I would not have got without the use of remote methods. By exploring the internet spaces carved out by people with chronic illnesses, I was often able do research in a way that engaged with the realities of the social lives of people who are unwell for long periods of time. Occupying these research 'bed spaces' (Piepzna-Samarasinha, 2018) alongside my participants allowed me to get to know my participants in an ethical and equitable way, and build up relationships which extended back into offline spaces when restrictions allowed.

1.5 Introducing research participants and groups

Below, I introduce the individuals and groups who took part in my research. I got to know all individuals online, before meeting some of them face-to-face after restrictions lifted. I was also an online member of the two support groups detailed below during this time, although none of my 'individual' participants came from these groups. I met everyone at the groups for the first time in person. In what follows, I have used pseudonyms and changed some identifying features in order to protect participants' identities. Those who wanted to picked their own pseudonyms. Similarly, when describing the socio-economic characteristics of where these women lived, I have used IMD data[5] (where known) in order to further protect anonymity whilst still providing important demographic data.

Individuals

Clare is a forty-something year old woman who lives with her son and their dog, Benny, on the outskirts of Durham. The area she lives in is not classed as particularly deprived in County Durham (top 40% most deprived), according to IMD statistics, but Clare herself lives in council owned accommodation and relies on state welfare support for her economic stability. Clare has a diagnosis of fibromyalgia, alongside a diagnosis of BPD (Borderline Personality Disorder). In the past she has experienced psychotic episodes, which mean she is often under the care of a CMHT (Community Mental Health Team). She was trained as a podiatrist, but has not worked for many years.

Ivy is a woman in her late sixties. She worked as a nurse for the majority of her life until retirement due to illness – she has a diagnosis of both fibromyalgia and arthritis, amongst various other things. After decades of battling for her symptoms to be believed, she obtained the fibromyalgia diagnosis just five years before I knew her. A few years ago, she lost her long-term partner, John, to Lewy-Body dementia. She now lives alone in a

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[5] IMD (Index of Multiple Deprivation) is a combined measure of deprivation in small areas (LSOAs – Lower Super Output Areas) within England. Each LSOA is given a score and is then ranked relative to all other areas, from most deprived to least deprived.

small village in rural County Durham. The area she lives in falls within the top 20-30% most deprived neighbourhoods in England. Her youngest daughter and granddaughters live nearby, and she spends a lot of time with them.

Chloe is a woman in her early twenties. Chloe was one of the youngest people I interacted with during my fieldwork. She was diagnosed with fibromyalgia the year before we began talking, but had had symptoms for as long as she could remember. She had left school at 16 and had been working as a makeup artist since then. She lives in a village not far from Sunderland with her partner, down the road from her parents, sister, and grandparents. The village she lives in is IMD decile 1, meaning it falls within the 10% most deprived neighbourhoods in England. About halfway through my research period, Chloe became pregnant with her first child. Consequently, many of our conversations revolved around the stigma she felt as a disabled mum-to-be.

Thelma identified herself to me as a *'disabled single mother of two disabled children'*. She lives in a small ex-mining community in Country Durham, Mountainhead, which falls within the top 20% most deprived neighbourhoods in England. Thelma is in her late thirties, and has lived with a diagnosis of CRPS (Complex Regional Pain Syndrome) since she was in her early twenties. CRPS is a rare disorder only thought to affect around 20,000 people in the UK, although estimates lack accuracy. Thelma had left school after finishing her A-levels. Alongside raising her children, Thelma runs her own small media business. She has family nearby who help out when they can, but Thelma raised her children mostly alone after divorcing her ex-husband, who was extremely abusive to her.

Jennifer is a married mum of two in her early forties, who lives in rural Northumberland. We never met up at her home, nor discussed her address, so I am unable to provide socio-economic data to describe her place of residence. She lives with her family and their two dogs and at the time we spent working together was undertaking a part-time master's degree in Psychology. She has a rare, painful, genetic disorder which was misdiagnosed for many years prior to the birth of her two sons. Her background is in counselling, and she works from home as a therapist. Much of the time we spent together was spent discussing pain and mental health, especially the links between trauma and the development of chronic pain.

Ella was almost thirty when we met. Importantly, she was in the process of preparing for her upcoming wedding. We spent a lot of time talking about these preparations, and the stress it was causing her. She had lived with fibromyalgia for many years, but had struggled to get a diagnosis until a few years prior to our meeting. She lived with her then-fiancé (now husband), and two dogs in a suburb of Newcastle. Although originally from Newcastle, she had spent many years living in Leeds (where she went to university) before moving back home. The area she lives in is in IMD decile 3, making it one of the top 30% most deprived neighbourhoods in England. Ella worked part time in an office job she felt very unhappy in. During the spring and summer of 2021, we met up regularly after she had finished work, to walk her dogs and discuss what was going on in her life.

Julie is a single mum of two teenagers. When we met she was in her mid-forties. She lives in the suburbs of Newcastle, but works as an overnight carer for a woman with MS (Multiple Sclerosis) in Leeds, a city around an hour away by train. She spent most weekends working away, and then spent the weeks recovering at home. She has a diagnosis of fibromyalgia. Because she worked so many hours, she found it difficult to access state support for her illness. We spoke mainly via text and over the phone when she was travelling to and from work, as this was the time she had free to speak to me. This means I am unable to provide any specific demographic information about her place of residence. However, we did manage to meet up in person in Newcastle for coffee once, in May 2021 where we discussed her military background and the fact she had moved around a lot during her life.

Andrea is a woman in her early fifties, who has a diagnosis of fibromyalgia. When we met, she worked full-time as an assistant in a children's mental health unit, which she found rewarding but difficult. She lived with her husband and children in a deprived rural part of county Durham, not far at all from where Ivy lives. A few months into us getting to know each other, she got a new job working in children's social services. This job had more regular (but longer) hours, and meant she had less and less time to talk to me. Throughout the time we knew each other, we only spoke virtually, in order to fit around Covid-19 restrictions and Andrea's work commitments.

Amy has a diagnosis of fibromyalgia, amongst other health conditions. She is one of the youngest participants I spoke to during my fieldwork (around my age – mid-twenties). At the time of my research, she was undertaking a remote master's degree at an elite university in the USA, with the hope of starting work full time soon after completion. She lived around 40 minutes' drive from Newcastle, towards the Tees estuary. I am not able to provide specific IMD data for her place of residence, but the LA (Local Authority – a larger area) in which she lived ranked 77/314 for deprivation in England at the time we were working together.[6] We spoke to each other via Zoom most often, but did manage to meet up in person when I was visiting her area.

Sophie is another relatively young participant, in her early thirties. She lived just outside of Newcastle, but had only moved there in her 20s, when she left home to go to university. She has a diagnosis of fibromyalgia, and works 4 days per week as an occupational therapist for people with learning disabilities. We spoke to each other mainly via Zoom on her days off, when she was feeling up to it, for a period of around 6 months. We never met each other in person, as Sophie was worried about her vulnerability to Covid-19.

Janet is in her early 60s and lived in a small town around 40 minutes' drive from Durham City. She had a fibromyalgia diagnosis, but at the time we knew each other was also recovering from a very painful frozen shoulder. She had worked at a carer for many years, but elected to take part in my research as she was not working for the first time in her life. This was due in part to her shoulder, but was also due to recovering from the grief she had experienced after the death of her father. Janet felt a lot of apprehension about contracting Covid-19, so we spoke over Zoom only, speaking regularly for a period of around 9 months. Due to this, I am not able to provide IMD data for Janet.

Mandy is in her forties and worked full-time for a big non-profit organisation in Newcastle, in a management role. She is educated to Master's level. She had been diagnosed with fibromyalgia in 2020, but had received no medical support after diagnosis, and rarely engaged with her GP. Instead, she self-medicated with OTC pain

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[6] This seems a pertinent place to highlight some of the contradictions that occur when using deprivation data. At the time we met, Amy was undertaking a very prestigious degree at an Ivy League institution, and was applying for well paid jobs within the UK civil service – two points which are important to consider when thinking about the complexities of socio-economic status, place, class and chronic pain.

medications. She had been working from home for the duration of the pandemic, which in her eyes made the hours she worked manageable. We spoke over video call during her work lunch breaks, and never met each other in person. As such, I am not able to provide any IMD data for where Mandy lived.

Chronic Pain Care

Chronic Pain Care is a chronic illness support group, which at the time of writing had been running for over 5 years. It describes itself on Facebook as follows:

> ‘Welcome to Chronic Pain Care
> We meet every Thursday at The House, Dinnington Moor
> 11am till 2pm with the crafting starting at 12.15pm
> We are a friendly group who promote positivity, we all know how negativity gets us down so lets keep things positive where possible. obviously if you want to have a rant, go on, we dont mind, we will help you see the better side of things where possible.’

Between September and December 2021, I visited the group weekly and participated in group activities. I also attended ‘extra’ activities, such as fundraisers and trips, for the duration of the time I spent living in Durham (up until 2023). As I never spent time with any of these participants in their homes, I am unable to provide IMD data to describe where they lived. However, Dinnington Moor itself has an IMD decile score of 4, meaning it is not classified as particularly deprived in County Durham, despite being in the top 40% most deprived neighbourhoods in England. All participants gave their verbal permission to be included in this thesis.

Several individuals are referred to by name throughout this thesis:

Iona is the group’s founder and organiser. She is in her late fifties and lived with fibromyalgia, ME and many other chronic conditions.

Gill helped Iona with a lot of the group organisation and finances. Gill is in her fifties and has a diagnosis of sarcoidosis, arthritis, and (with the help of the group members) had also figured out she had all the symptoms of fibromyalgia.

George and Mildred have been married for many years. They are both retired; Mildred lived with fibromyalgia, and George was her full-time carer. They have a grandson, Oliver, who often attended the group with them.

Maeve is George and Mildred’s good friend, who had also recently retired. Maeve had a lot of back pain from an operation she had had years before, but mainly attended the group for emotional support after the recent and sudden passing of her husband.

Edna is in her eighties. She had severe arthritis. George and Mildred drove her to the group every week, as she was unable to get there alone. Edna was the oldest member of the group, and was looked after by many of the group members.

Linda did not have a diagnosis of fibromyalgia, but lived with severe arthritis. She is in her late fifties and had had several strokes in the past few years, which had left her with nerve damage that caused her a lot of pain.

M.H.P.S.G (Mental Health and Pain Support Group)

M.H.P.S.G is a chronic illness and mental health support group which was run out of a community centre in a post-industrial coastal town. As with Chronic pain care, the community centre where the group was held was in an IMD decile 4, meaning it is not classified as particularly deprived for County Durham. However, the town the group was held in itself had all the classic hallmarks of post-industrial decline and neglect – a very good example of the 'left behind' neighbourhoods described above. On Facebook, M.H.P.S.G describes itself as follows:

> 'This group is set up to help those with fibromyalgia and chronic pain and their Carers. Help and support pain management, welfare and job club support, alternative therapies, healthy eating as well as general chit chat'

There had been attempts to set up a group of this nature in the area for years, but they had been thwarted by Covid-19. In September 2021, there was a drive to start a group that would be able to run weekly, and would take place face-to-face. I attended the first of these meetings, and then began attending the group on a weekly basis until December 2021. M.H.P.S.G was quite different from Chronic Pain Care, in the sense that it was a much newer group with far fewer members. It did not have the funding, nor the history of Chronic Pain Care.

As the group was newer, fewer members came regularly. At the very most, ten people attended the group on any given day. All those who came gave their consent to be written about in thesis. The main members, who are spoken about most frequently are:

Becky is the group's founder, and main organiser. She is in her early fifties, and has a diagnosis of fibromyalgia. She was also suspicious that her pain had another cause, such as Lupus.

Mia's husband worked in the community centre where the meetings were held, and had directed her towards the group. At the time I knew her, she was in the process of obtaining her fibromyalgia diagnosis, which she received in November 2021. She was in her mid-forties at the time of her diagnosis.

Donna is a younger woman, in her early thirties, who attended the group when she could. She had a fibromyalgia diagnosis, alongside a diagnosis of BPD (Borderline Personality Disorder) and ADHD (Attention Deficit Hyperactivity Disorder).

1.6 Thesis outline

I will now briefly outline the form this thesis takes. After this introduction, Chapter Two will provide an overview of my theoretical orientation and the key literature important to this thesis. After this, the main body of the thesis is split into three main sections; the past (or what happened before), the present (or, living under diagnosis) and the future (?). Each section has chapters within it, which I outline below.

Section One: The Past (or, What Happened Before)

In this section I explore how my participants view their own pasts, and how the stories they tell about the origins of their chronic pain are always oriented 'looking backwards'. It is split into two chapters:

Chapter Three: Trauma and Violence in North East England

This chapter discusses how ideas around trauma and past experiences of violence are infused into illness narratives around the aetiology of chronic pain. Many participants had been subject to various forms of violence throughout their lives. This chapter does not go into the intimate details of this violence, but instead contemplates how violence is engaged within biomedical and psychological models of the causality of chronic pain. By exploring how participants understand their own experiences of violence in relation to their pain, I argue that the direct casual relationships that are sometimes drawn between violence and the genesis of chronic pain fail to engage with the structural factors that shape the lives of my participants.

Chapter Four: Diagnosis Histories

Building upon the above discussion of violence and pain, this chapter argues that the origin stories of my participants' chronic pain were often grounded in the stories told about how a diagnosis occurred. In this sense, how a person was diagnosed constitutes a huge part of their past, but also their identity in the present. I use my participants' own diagnosis histories to illustrate this. Drawing from older sociological work on diagnosis, I explore how obtaining a diagnosis can be both a category (something a person is placed into) and a process (something that happens to someone) (Blaxter, 1978). I draw on Hacking (1995)'s 'looping effects of human kinds' to explore how the diagnostic categories which surround chronic pain 'loop and loop' and are altered as people enter them. Consequently, the process of getting a diagnosis can alter how a person perceives their past, but also how they live in the present and conceptualise the future.

Section Two: The Present, Or Living Under Diagnosis

This section describes how daily life is experienced while living under diagnosis. It focuses on what happens after a diagnosis is obtained and considers how chronic pain can impact life in the everyday.

Chapter Five: Chronic Illness at the Borderlands

This chapter aims to understand what it is like to interact with healthcare systems while living under a diagnosis of chronic pain. Building on the previous chapter, which traces the long and difficult process of obtaining a diagnosis, here I demonstrate that even after a diagnosis is obtained, chronic pain patients still occupy a space of liminality. Using Anzaldúa (1987)'s *Borderlands/La Frontera*, I focus on what happened to my participants during healthcare encounters. Even with a diagnosis they often occupied a place between 'not sick enough' and 'too sick'. I use ethnographic examples to understand further the difficulties people had accessing care for their various diagnoses, and also consider how these diagnoses themselves can serve as a barrier to care. This chapter argues that 'living at the borderlands' meant that my participants developed what Anzaldúa (1987) refers to as *la facultad* – a special knowledge which only occurs through marginalisation – around their experiences of healthcare.

Chapter Six: Gender, Sex, Motherhood and Pain

This chapter discusses how themes of violence and forms of marginalisation link together with the gendered and sexed aspects of living under a diagnosis of chronic pain. Using literature from within the social sciences and humanities regarding the socially constructed nature of gender and sex, it explores what it is like to live under diagnosis as a chronically ill 'mam'. Using my participants' experiences as women who live with chronic pain, I argue that the experience of living in a gendered body contributes to the biological (and embodied) experience of pain in the everyday.

Chapter Seven: What Substances Work?

In this chapter, I describe the everyday use of different 'substances' that form part of chronic pain management in the North East. Using the biographical approach I had originally intended to apply to this entire thesis, I explore the use of prescription opioids alongside over-the-counter medications, and illegal/diverted drugs in the management of chronic pain. Through this approach, I demonstrate that the substances used to manage chronic pain extend far beyond prescription painkillers taken as directed by clinicians. What is important to those who use different substances to manage chronic pain is not how and when (or even if) they were prescribed, but rather 'what substances work' to manage pain.

Chapter Eight: Biocitizenship, Traumatic Landscapes and Access to State Benefits in North East England

The final chapter in this section draws together themes that run throughout this thesis. I discuss how life under diagnosis often required my participants to find novel ways to obtain biocitizenship, in order to gain access to social welfare and other forms of support. I also reflect on the links that exist between geography, deprivation, sickness, and engagements with the welfare state. To do this, I use Petryna, (2002)'s *Life Exposed* alongside Proudfoot (2019)'s idea of the traumatic landscape, to consider the forms of violence that link together place and health in North East England.

Section Three: The Future(?)

Chapter Nine: Living through Crip Time and the Subjunctivity of Chronic Illness

In this final ethnographic chapter, I look to how the future is perceived and imagined by those living under the diagnosis of chronic pain. I firstly argue, following Whyte (2002), that living with chronic illness means that my participants live 'in the subjunctive'. The subjunctive is a specifically future oriented mood, which emphasises the importance of 'chance' that comes alongside living with chronic pain. While living with chronic pain, the future is measured against the present, and choices are made about activity based on the pain these activities may cause in the future. In the second part of this chapter, I contemplate why people choose to do these pain-causing activities, and discuss the importance of hope and community in governing how chronically ill people live with many potential futures in mind. While living under a diagnosis of chronic pain entirely changes a person's relationship with the future, I conclude that sometimes the present takes precedence in order to create fun, joyful and socially connected lives.

Chapter Ten: Conclusion – Chronic Pain Futures

The conclusion to my thesis sits within 'The Future (?)'. Here, I return to my research questions, and contemplate the theoretical and practical contributions this thesis makes both within medical anthropology, and more broadly. Most importantly, I consider how thinking about ‘chronic pain futures’, can provide the possibility of world oriented towards disability justice.

2 Chapter Two: Theoretical Orientation and Key Literature Review

This chapter discusses some of the key theoretical perspectives and bodies of literature central to how I have analysed and articulated the findings of this thesis. Threads of this literature appear in the ethnographic chapters. By introducing the key areas here, I want to draw attention to the complementary nature of much of this work, and how I have considered what is presented below as a being a body of collective theory. I have organised this literature review to be roughly in line with the way the literature appears in the thesis itself, but here want to emphasise the overlapping nature of many of the concepts detailed below.

In this chapter, I first discuss my epistemic position as a critical feminist disability anthropologist. This perspective is important as it has shaped both *what* I focused on during my fieldwork, and also *how* I have written about it. Secondly, I discuss anthropological perspectives on both pain and violence. From here, I consider some of the key theoretical perspectives on diagnosis, which have been important to how I have understood and articulated my data. After considering these perspectives, I look to the wide range of literature focused on the constructed nature of both sex and gender. I ask how looking to feminist thought can help medical anthropologists to 'take biology seriously' (Wilson, 2015: 13). This is followed by an overview of the interlinked, but often distinct, anthropological literature on pharmaceuticals, drugs and opioids. After this, I explore the twin concepts of biosociality and biocitizenship, and reflect on their usefulness for my work. Finally, I provide an overview of ideas around time, futurity and hope from the perspective of both medical anthropology and disability studies.

2.1 Epistemic position: Critical feminist disability anthropology

My research was always going to be feminist research. This was not only because most of my interlocutors were women, but because of the way I navigated relationships with participants. Throughout my research, and even now as I am writing up, my primary concern is the wellbeing and authentic representation of the people I met during fieldwork. This approach has a history. Feminist anthropological research has often aimed to challenge the problematic models of anthropology which place white men as the ethnographers and people of colour as the subjects of research. These histories can be traced all the way back to the (often ignored) ethnographic work of Zora Neale Hurston (Hurston, 1937; Mikell, 1983), through to the critiques of scientific objectivity of the 1980s (Haraway, 1988). From my perspective, I follow most closely Mahmud (2021)'s view of feminism in anthropology. I do this through playing attention to 'traveling theories of bodies and power' (Mahmud, 2021; 355), working with ideas of embodiment and power that came up during fieldwork through an explicitly feminist framework.

This feminist epistemology also plays out in my writing. To the best of my ability, I have attempted to shape my work using Sara Ahmed's concept of 'citational politics'. In *Living a Feminist Life,* Ahmed (2017:15) explains this concept as follows:

> 'citation is how we acknowledge our debt to those who came before; those who helped us find our way when the way was obscured because we deviated from the paths we were told to follow'

The shift in my original research plans away from opioids and other painkillers also meant a shift in my citational politics. In this thesis I have tried, where possible, to include a broad range of perspectives that exist outside of the typical anthropological canon. Of course, there are places where engaging with more 'traditional' perspectives from anthropology and philosophy more broadly was important, such as my engagement with Hacking (1995)'s 'looping effects', or through Rose and Novas, (2005)'s analysis of biosociality and biocitizenship. However, where possible, I have used perspectives from black and brown feminists of colour, critical theory, feminist technoscience(s), and disability studies, to bring into my work a wide and full range of perspectives.

The second strand that has informed my epistemic position is disability anthropology. I was working, for the most part, with individuals who identified themselves as *disabled* women. My research was therefore always going to exist somewhere at the intersection of feminist disability studies and medical anthropology. To do this, I turned to Hartblay (2020)'s disability anthropology. Hartblay draws an important distinction between 'disability anthropology' and the 'anthropology of disability'. She argues that medical anthropologists have historically viewed disability as being a subject of study from within the sub-discipline of medical anthropology itself. However, Hartblay explains that a true disability anthropology needs to engage with insights from disability studies. By doing so, it is possible to produce a truly interdisciplinary perspective on disability, which foregrounds the experiences of disabled people. To do this, medical anthropologists must engage with the perspectives of disabled scholars and draw from texts from within disability studies to inform their analysis. I hope it is clear throughout this research that I have done this wherever possible.

The third strand that informs my epistemic position is that of critical medical anthropology. This body of literature spans from the early 1980s to the present day. It is concerned with playing close attention to the macro forces that govern global political economies, in order to understand micro level, everyday aspects of health (Singer, 1986). Fundamentally, critical medical anthropology takes the position that by exploring power relations, the structural origins of poor health can be exposed (for examples see: Baer, 1982; Singer, 1986, 1989, 1995; Kapferer, 1988; Scheper-Hughes, 1990; Bourgois, 2003). It aims to situate individual troubles in their wider structural context (Singer, 1989) and questions the premises often presented as static truths in biomedicine (Scheper-Hughes, 1990). These themes are ever-present in this thesis, and perspectives which consider the structural factors that govern health will be discussed at length as it progresses.

Informed by the feminist perspectives described above, I concluded while writing up that I am a 'critical feminist disability anthropologist'. This wordy descriptor represents something deceptively simple; I am a socio-medical anthropologist who works on issues of disability, while focusing on power dynamics in society. In other words, this thesis takes feminist methodologies, and combines them with insights and theoretical approaches from within critical medical anthropology (Van Hollen, 2016). Attending to Hartblay (2020)'s disability anthropology is central to becoming a critical feminist disability anthropologist. By doing so, I hope to demonstrate close ethnographic attention to the lives and stories of my participants, engaging with and representing their words and world-views as they see them as much as is possible.

2.2 Pain and violence

2.2.1 Perspectives on pain: anthropology and critical theory

The ICD-11 defines chronic pain as pain that persists for longer than three months, and is associated with 'significant emotional distress or functional disability' (Word Health Organisation, 2022). Of note for this thesis, chronic pain creates problems for biomedicine; it provides challenges for systems of classification and exists well outside of traditional cartesian models of mind-body dualism (Good *et al.*, 1992). However, the experience of pain is an almost universal human experience. The study of pain is therefore of significant importance to anthropology. It reflects the 'fault lines of society' and draws attention to issues which run from the structural to the cellular (Good *et al*., 1992:3).

In the latter half of the twentieth century, social scientists began to study *chronic* pain. This can be most notably traced to the work of Zborowski (1969) and Kortarba (1977, 1983). Zborowski (1969)'s work in particular tends to be cited as some of the first anthropological research which looked at chronic, rather than acute, pain. This research was carried out in the United States, and was mainly focused on how patients adopted the sick role, alongside the influence of culture on how pain was experienced and articulated. As a body of literature, it has been criticised for very basic and essentialising understandings of 'culture', alongside a lack of nuance when considering the pain experience itself (Good *et al.,* 1992). However, by attending to these origins, it is possible to trace a lineage of chronic pain research within the social sciences.

Alongside this work within the social sciences sits Scarry (1985)'s *The Body in Pain: The Making and Unmaking of the World.* Throughout this canonical critical theory text, Scarry foregrounds the body as the key epistemic structure through which pain should be theorised. The central argument in the text is that pain is next to impossible to communicate through language – it is a radically private discourse, which can only be felt through experience. In recent years, critiques have emerged of Scarry's use of an ontology which takes Cartesian dualism as a given (Dawney and Huzar, 2019). However, the text itself remains essential to discussions and debates about how pain is felt, understood, and communicated. Scarry's theorisation of pain is central to how pain has been written about the social sciences, and beyond.

Another critical theory text that has heavily influenced pain theory is Morris (1991)'s *The Culture of Pain.* Here, Morris argues that pain is much 'more than nerves and neurotransmitters' (Morris, 1991:2) and aims to interrogate the complex meanings that emerge when pain is phrased purely as a biochemical problem. He argues that the advent of the 'pain clinic' (a specialised treatment centre for chronic pain states) is central to how chronic pain has been constructed. Importantly, a key argument in this text is Morris' idea of the 'myth of two pains'. He strongly argues for the collapsing of the idea of physical pain vs. mental pain as bounded categories. Written half a decade after *The Body in Pain,* Morris (1991)'s ideas complement and supplement Scarry's. Together, these two texts focus on how pain is communicated, articulated and described in both popular and clinical settings.

Scarry and Morris changed the wider landscape of pain theory. In 1992, Good *et al.* published *Pain as Human Experience*. This text has had a huge impact in the anthropology of chronic pain, and is cited numerous times in this thesis. It explicitly argues that anthropology needs to move beyond the 'cardboard characters' created in Zborowski's anthropological work on pain. The authors argue that Zborowski's work fails to employ lived experience as its central mode of inquiry, and therefore does not constitute good anthropological work (Good *et al.*, 1992:2). *Pain as Human Experience* explicitly positions chronic pain within the structures that influence it. It emphasises anthropology's responsibility to explore the gaps between physical and psychological approaches to understanding pain. The authors argue that pain is resistant to both medical and ethnographic analysis, concluding that the only way to understand pain is to place the personal experience of pain right at the centre of analysis. This is something I have taken to heart while writing up this thesis.

After the publication of *Pain as Human Experience,* anthropologists began to explore pain further. After the year 2000, research became focused on narrative and meaning making (Jackson, 2000; Throop, 2008; Buchbinder, 2010) cultural expressions of pain (Throop, 2008) and how personhood is formed through clinical encounters (Buchbinder, 2011, 2012). Many of these publications complement my ethnographic work, and so will be discussed in further detail in the body of the chapters themselves. The majority of research published was grounded deeply in ethnography, and centred around the experiences of both adults and children in pain clinics in the US (Jackson, 2000, 2005; Buchbinder, 2011, 2012). More recently, Eaves, Nichter and Ritenbaugh, (2016) have focused on the role hope plays in the lives of those living with chronic pain.

During the last 50 years, since the introduction of the pain clinic as both a therapeutic and a research space, anthropologists have explored chronic pain in various ways. Using the theoretical ideas that have their origins in the work of Scarry (1985) and Morris (1991), anthropologists have explored how pain operates within and beyond biomedicine. Ethnography has emerged as a key method through which the lived, untold, experiences of pain can be carefully uncovered. Extended pieces of fieldwork as undertaken by Jackson (2000;2005) and Buchbinder (2011;2012) have demonstrated what thick description can bring to understanding chronic pain, from the perspective of those experiencing it.

2.2.2 The anthropology of violence

Alongside (and interlinking with) this growing work on pain, three key volumes on violence were published by a group of anthropologists in the 1990s and early 2000s (Kleinman, Das and Lock, 1997; Das *et al.*, 2000; Das, Kleinman and Lock, 2001). Indeed, *Pain as Human Experience* and the volumes detailed below share a common author in Arthur Klienman. These three volumes, published over the course of four years, explore the concept of violence in anthropology using a comparative ethnographic perspective. The first of these, Klienman, Das and Lock (1997)'s *Social Suffering,* places emphasis on the interweaving of suffering and global political economies – suffering is, inherently, a social experience. After this, Das *et al.,* (2000) published *Violence and Subjectivity,* which aimed to ask 'anthropological questions' about the links between violence, institutions, communities and individual experiences. The final volume, *Remaking a World* (Das, Klienman and Lock, 2001) looked at how communities 'cope' with violence, and seek to rebuild their everyday lives after violent events.

Following these three linked volumes, Das, (2007)'s *Life and Words: Violence and the Descent into the Ordinary* explores the more mundane aspects of living through, and after, violence. She argues that anthropologists need to look to the everyday details that surround catastrophic events, herself focusing on the aftermath of the 1947 Partition and the assassination of Indira Gandhi in 1984. By doing so, Das places emphasis on both the 'ordinary' and the 'everyday' as key ethnographic field sites, which can help to inform thinking about how violence impacts people throughout their lives.

The approaches seen in these linked volumes place importance on the interpersonal, and implicit, experiences of violence, and how they play out in the everyday. By exploring the impact of specific violent events, for example the 1947 partition, this body of work looks to understand the kinds of 'ripple effects' violent events can have, and the ability of these events to 'make and unmake' social worlds. Furthermore, Scheper-Hughes and Bourgois (2004:1) have famously discussed the ambiguous nature of violence, writing of a 'continuum of violence' that is 'slippery' and hard to define. Fundamentally, the 'anthropology of violence' looks at the intangible way violence is felt and talked about in the everyday. This is not unlike Scarry (1985)'s understanding of pain, discussed above.

While these approaches do explicitly consider the impact of socio-economic marginalisation on individuals and communities, the body of work surrounding the 'anthropology of violence' focuses mainly on the impact that defined violent events have on the banal aspects of everyday life. Indeed, much of this work focuses on the impact of large-scale violent events on human life: colonial conquests, war, genocides, mass killings. These perspectives can be well demonstrated by looking to Taussig (1984)'s article 'Culture of Terror—Space of Death. Roger Casement's Putumayo Report and the Explanation of Torture' alongside the later full length monograph *Shamanism, Colonialism and the Wild Man: A Study in Terror and Healing* (Taussig, 1991). In this influential work, Taussig discusses the narratives and discourses that emerge around the understanding and explanation of violent events. Often, he argues, violent events are understood through a 'dense web of magical realism' (Taussig, 1984: 469) which brings together the elements of fact and fiction that always occur at the margins of the ethnographic exploration of violence.

As will become apparent, I consider these perspectives useful for thinking about the kind of 'folding' of violence into the everyday that Das (2007) has written about so extensively. However, for my participants, their experiences of violence were often cumulative, slow, ill-defined, and unbounded. While some participants did experience catastrophically violent events in their lives, which became a defined part of their pasts, often the violent events experienced were ongoing and emerged structurally. These events were mediated through the state, society, the medical establishment, and through gender.

2.2.3 Structural violence

The violent events that structured the lives of my participants were baked into social structures, through long histories of industrial decline and the ongoing austerity policies that have significantly impacted health in the North East (Dorling, 2010; Bambra and Garthwaite, 2015). For my participants, the violence that touched their lives cannot be explicitly linked to any one event collectively experienced by communities. Instead, the concept of structural violence can be best used to describe the experiences of everyday violence my participants were subject to. The concept of structural violence itself is most often traced back to Galtung (1969) who first differentiated between 'personal' and 'structural' forms of violence. From here, the idea of structural violence has been adopted widely within health research, especially that focused on health equity (De Maio and Ansell, 2018).

This health focus can be most famously seen through the enormous body of literature produced by physician-anthropologist Paul Farmer on the topic (Farmer, 1992, 1996, 1997, 1999, 2004a, 2004b, 2019). While structural violence is now a relatively 'old' concept in medical anthropology, it continues to hold theoretical weight today. By looking closely at the ‘social machinery of oppression’ (Farmer, 2004a: 307) we can understand the health impacts of a ‘political and economic order as old as slavery’ (Farmer, 2004a: 317). Throughout Farmer’s work, links are continuously drawn between colonialism, global poverty, capitalism, and the health of global populations today.

These ideas of structural violence fit within the anthropology of violence more broadly. In Klienman *et al.’s* (1997) *Social Suffering*, Farmer (1997) cemented his view of structural violence as sitting deeply within the anthropology of violence with his chapter *‘*On Suffering and Structural Violence: A View From Below’. Here, Farmer draws from long-running ethnographic work on the HIV/AIDS epidemic in Haiti (Farmer, 1992) to illustrate how violent social forces shape the suffering experienced by individual people. This work is distinct from other chapters featured in this volume, which are focused on broader theoretical concerns such as how ‘torture’ or ‘death’ are understood and experienced socially. It is for this reason I consider this body of literature as being conceptually separate from the anthropology of violence, and use it as such in this thesis.

To do this effectively, I must engage with some of the critiques and concerns which have been levied as a challenge to those writing on structural violence. Commentary on Farmer (2004a)’s ‘An Anthropology of Structural Violence’ reveals an excitement for the growing use of the concept, alongside several concerns. Philippe Bourgois and Nancy Scheper-Hughes, both of whose work has been influential for this thesis, express concerns of structural violence becoming an academic ‘black box’, much in need of refinement and redefinition to be useful outside of the academy. They argue that ethnographers need to be more explicit in their usage of the term, in order to ‘contribute by rendering visible these erased and unexpected linkages between violence, suffering, and power’ (Farmer, 2004a: 318). Rather than simply using structural violence as an overarching framework, in this thesis I try to highlight instances and examples of how it works in practice.

Furthermore, Linda Green (Farmer, 2004a: 219) argues that Farmer does not take his work on structural violence far enough, and instead draws on simplistic binaries drawn between ‘dominated/oppressed’ peoples and those who study them as a key metric of analysis. She argues that to use structural violence effectively, ethnographers must address the ways state-sponsored violence is ‘reworked through the routines of everyday life’ (Farmer, 2004: 320). This is a critique I take seriously, and have attempted to incorporate by structuring my thesis around the more ‘mundane’ elements of chronic pain in everyday life.

Finally (and most damningly), Loic Wacquant describes Farmer’s concept of structural violence as ‘conceptually limited and limiting’ (Farmer, 2004a: 322). He argues that Farmer’s analysis of violence is moralistic, thin, and at times anachronistic. As such it becomes a rhetorical tool used to describe violence, rather than change the ‘tangled knot’ of social structures which surround it. The use of structural violence as a rhetorical tool is something I have worked to avoid throughout the writing of this thesis. By using structural violence as a key theoretical tool, I aim to draw attention to the broader social structures which trickle down into the everyday lives of my participants. In this thesis I aim not to simply describe the things that happened to my participants, and the social forces which may have caused them. Instead, I look both at how individuals understand these forces, both in their pasts and in the present day, and how they navigate, and even resist them. However, I argue the first step in doing so is to understand the lives of my participants through the lens of structural violence.

2.3 Key perspectives on diagnosis

2.3.1 Living under diagnosis

As will be apparent in the language I have used while writing so far, I consider a diagnosis as being something someone 'lives under'. This follows the language used in Martin (2007)'s *Bipolar Expeditions*. Martin's ethnography focuses of the lives of people in the United States, including the author herself, who live under a diagnosis of bipolar disorder. My use of this terminology was inspired by Manderson (2020), and also by a much earlier reading of Martin's work. I first read this ethnography in 2017, during my MSc in Global Mental Health, and was struck by the attention Martin paid to the language around illness, alongside the role of support groups in the management of stigmatised conditions. When writing about the language used to mobilise diagnostic categories, Martin chooses to describe her interlocutors (and herself) as 'living under' the diagnosis of bipolar disorder, emphasising that the point of being given a diagnosis creates a rupture from which life changes (Martin, 2007: 10). This idea resonates with my participants' experiences; the symptoms have always existed, but a person comes to 'live under' diagnosis at a specific point in time.

By following Martin, and referring to my participants as living under a diagnosis of chronic pain, I draw further attention to the broad (and often 'looping') nature of chronic pain states. As demonstrated in my introduction, the symptoms that constitute the everyday experience of living with chronic pain can often fit into multiple different categories, and are viewed in different ways by the biomedical establishment. Furthermore, the idea of 'living under' diagnosis places emphasis on the impact that a diagnosis can have upon how a person views what has happened to them in the past, and how they experience life in the present. Finally, 'living under' diagnosis can dictate how a person understands what 'might' happen to them in the future.

2.3.2 The looping effects of human kinds

In 1995, Ian Hacking, a philosopher of science, published a complex and heavily theoretical text entitled 'The Looping Effects of Human Kinds'. I came across this piece of work through Ecks and Harper (2013) and soon realised it held importance to this thesis much more broadly. In it, Hacking describes how different systems of classification (or, when focused on this thesis, diagnostic categories) are rooted not in the 'natural sciences' in the way that plants or animal taxonomies are, but are created through the cataloguing of people. He describes these systems of classification as 'human kinds', and separates them from the 'natural kinds' that are seen as 'pre-existing' within nature. Examples of these 'pre-existing' categories are natural phenomena such as the sky, mud and animal taxonomies. Of course, the ways humans categorise plants, animals and even rocks are themselves socially constructed. Hacking does not dispute this, but instead argues that there is something philosophically useful in looking at the distinctions drawn between 'human kinds' and 'natural kinds'.

It is important here to reiterate that Hacking's philosophy does not make claims about the objective reality (or not) of these human or natural kinds. When 'human kinds' are described, they are often 'patterned after the efficient causation of the natural sciences' (Hacking, 1995:365). This language of causation is used to describe 'natural kinds' and to create the impression that they are pre-existing in nature. Here, Hacking is not arguing that 'natural kinds' exist outside of human control. He rather states that certain scientific and biological language techniques are used to describe these natural kinds. Hacking observes that when human kinds are described, the language of the natural sciences (and natural kinds), are used to infer ideas around causality and naturality. The systems of classification that create human kinds mirror the rules expressed in the natural sciences, and are used to create expectations of predictability, or 'normal' behaviour, within a given diagnostic category. When Hacking (1995) talks about human kinds vs natural kinds, he observes how the systems of classification used within human social life are often aligned with ideas of 'science' or 'biology' to infer a deeper reality.

Importantly, there are 'looping or feedback effects involving the introduction of classifications of people' (Hacking, 1995: 362) which occur when different diagnostic categories are created. Diagnostic categories can change as more people with various symptoms or experiences are included within a given category. For example, if various people who fall within the category of 'fibromyalgia' experience a symptom not previously thought to be associated with the condition, the symptoms may loop and loop, and in turn become part of the official diagnostic criteria. This is why thinking with these looping effects in mind can be enlightening; they can show us how diagnostic categories are not static, pre-existing or a-temporal, but are altered as more and more people enter and leave them.

Hacking (1995) uses the example of the creation of the category of 'child abuse' in the twentieth century to provide an example of the 'looping effects' that occur when systems of classification are created and become self-fulfilling. Hacking explores how the 'human kind' of child abuse came to be seen as a scientific concept only after the 1970s. He observes how, at this time, literature on child abuse became influenced by the psychological literature of the time, and child abuse became classified as a pathological behaviour. He observes how experiencing abuse oneself as a child became as a strong *predictor* for becoming a preparator of abuse later in life. These patterns follow the kinds of 'laws' of inheritance popular within the natural sciences. As a consequence, the laws surrounding child abuse risk became incorporated into biomedical, legal and carceral frameworks. When 'child abuse' becomes a category – a human kind – it allows expectations about behaviour to be formed, and for descriptive law-like statements about people who abuse children to be created.

While drawing philosophical distinctions between things well understood by anthropologists as being socially constructed might seem antiquated, Hacking's work can demonstrate *why* these looping effects are so important. This is for two reasons. The first is that when thinking about the diagnosis of chronic pain states (and other 'invisible' illnesses), Hacking's work can help to understand how diagnostic categories are made 'real'. Hacking refers to this process as the production of a 'biologised kind' – he argues there is a 'built in metaphysical motivation for biologising human kinds' (Hacking, 1995: 354). If the contested conditions (or human kinds) central to my thesis can become seen as being subject to laws of natural causality, they become more real and therefore more believable.

Secondly, as these diagnostic categories loop and loop, and more people enter them, they become further under the control of the people who exist within them. This is something Hacking calls a 'self-ascriptive kind', where different groups of people begin to control the groups ascribed to them. This occurs through the production of 'self-help' groups, which feature heavily throughout this thesis. Hacking argues that these self-help groups can begin to re-moralise the human kinds previously used for negative administrative purposes. Through the creation of these self-ascriptive kinds, Hacking observed that 'we are experiencing a wholly new type of looping effect, when so many of the kinds claim rights to their own knowledges' (Hacking, 1995: 382). For example, categories of homosexuality were previously used to classify certain parts of the population as pathological and deviant. Through the creation of self-advocacy groups (alongside many other factors), the category of homosexuality has, for the most part, 'looped out' of being seen as a pathological mental illness.

In the case of chronic pain, 'self-ascriptive' kinds consist of the support groups I interacted with extensively throughout my fieldwork. In these groups, people were welcomed regardless of whether they lived under a specific diagnosis given by a medical professional. Recently, Bradley (2021) has written about the links between these looping effects and patient experience through her ethnographic work on bodily focused repetitive behaviours (BFRBs). Here, Bradley draws important links between forms of biosociality (which will be discussed later) and the looping effects which are the focus of this section, cumulating in the production of something she terms 'biosolidarity'. As will be shown throughout this thesis, the painful symptoms and experiences which looped into different diagnostic categories were a starting point from which social connections and knowledge was exchanged by my participants.

Through an understanding of the function of the biological language used to describe the different 'human kinds' that surround chronic pain, it is possible to understand further how diagnoses occur and are maintained in the everyday. In this thesis, I consider the processes via which a person comes to live under (and how they understand) the diagnoses central to this thesis. They can help to illuminate the social forces that allow, or perhaps prevent, a person from looping into, or out of, a specific human kind.

2.3.3 Borderlands/La Frontera

As people become absorbed into different diagnostic categories through the looping effects described above, they cross and alter boundaries. To explore this further, I have found Anzaldúa (1987)'s *Borderlands/ La Frontera: The New Mestiza* useful to think with, in order to understand the kinds of liminality experienced by participants while they were seeking healthcare.

Gloria Anzaldúa was a Chicano lesbian feminist scholar, who wrote extensively about the role of borders – both physical and psychic – in the lives of marginalised people. Her famous work *Borderlands/La Frontera* is a semi-autobiographical collection of poetry and prose exploring her experiences growing up on the US/Mexico border, and the forms of violence she experienced there. It is written half in Spanish, half in English, meaning half of the text (unless the reader's linguistic ability stretches across borders) is intentionally difficult to interpret. In the text Anzaldúa illustrates the importance of her identity to the conclusions of the book. Her marginalisation granted her a very specific way of interpreting and understanding the world. The key idea in this text is concerned with how identities which exist 'in between and beyond' worlds dictate the way a person navigates the world. She describes this as experiencing life 'at the borderlands'.

Anzaldúa defines borders as follows:

> ‘Borders are set up to define the places that are safe and unsafe, to distinguish us from them. A border is a dividing line, a narrow strip along a steep edge. A borderland is a vague and undetermined place created by the emotional residue of an unnatural boundary. It is in a constant state of transition’ (Anzaldúa, 1987: 25)

This definition can easily be applied to those living under a diagnosis of chronic pain. Often, as I show later in this thesis, my participants had waited years to enter the ‘vague and undetermined’ place they called their diagnosis. Even then, they faced regular push-back and disbelief when they sought medical care, and their clinician’s belief in diagnosis was always contingent on them being ‘sick enough’ to warrant care, assuming the resources to provide such care existed. In *Borderlands/La Frontera*, Anzaldúa describes the concept of *la facultad* – the specific kind of awareness a person obtains through living in a world which marginalises them. *La facultad* can be best understood as being a ‘sensing’, or ability to ‘see in the surface phenomena the meaning of deeper realities' (Anzaldúa, 1987: 60). Through *la facultad*, people become attuned to the dangers that exist in the world around them, and learn how to facilitate their own survival. As I discuss throughout this thesis, many layers of intersecting marginalisation (or perhaps more aptly, structural violence) combine to create the lives lived by my participants. These factors influence how they navigate their lives and the knowledge they develop about the world.

Although not writing specifically about chronic illness in the text, Anzaldúa lived with multiple chronic illnesses throughout her life. Critical theorists have, posthumously, documented the role that pain, disability and chronic illness must have had on her writing (Bost, 2010, 2019; Vallone, 2014). It is partially for this reason that I decided to place her work at the centre of my thinking, rather than focusing on more traditional understandings of liminality that have pre-occupied anthropologists for decades (Turner, 1966). Although Anzaldúa’s work is focused mainly on the violence of physical borders, namely the US/Mexico border, I use her work in this thesis to explore the intangible knowledge gained by women who live under a diagnosis of chronic pain in the North East.

2.4 Gender and sex: Leaky bodies and gut feminism

2.4.1 Gender and sex in feminist thought

Gender undoubtedly contributed to the forms of marginalisation which led to my participants’ positions ‘at the borderlands’ when seeking healthcare. Gendered discrimination in healthcare encounters is well documented (Govender and Penn-Kekana, 2008; Bates, Hankivsky and Springer, 2009; Read and Gorman, 2010; Ayhan *et al.*, 2020) and becomes further complicated when it intersects with race and class (Viruell-Fuentes, Miranda and Abdulrahim, 2012; Lewis *et al.*, 2017; Kapilashrami and Hankivsky, 2018; Gillispie-Bell, 2021; Palmer, Cozier and Rosenberg, 2022). Indeed, the explicit links made within biomedicine about a causal link between gender and chronic pain is something which haunted my fieldwork (Creed, 2020).

The main focus of Chapter Six is to discuss feminist ideas around gender and sex and to deconstruct further some of the essentialist ideas about ‘womanhood’ which have emerged since the enlightenment period (Shildrick, 1997) in the context of chronic pain. However, an understanding of these ideas is very important to this thesis more broadly. The origins of this thinking can be traced back to movements regarding women’s reproductive freedoms during the 1970s (Roberts, 2003) and from there to theory which emerged in the late 1980s and the early 1990s.

Two key texts published during this period were Butler (1990)'s 'Gender Trouble' and Haraway (1987)'s 'Cyborg Manifesto'. Both texts make a similar point at their core; that there is no inherent link between sex and gender. Gender is, as Butler argues, 'performative', in the sense that it is constructed through the repeated acts of the everyday – 'feminine acts' produce 'female bodies'. This means that the performance of both gender and sex is inherently socially constructed and self-replicating. However, as Haraway (1987) states:

> 'There is nothing about being female that naturally binds women. There is not even such a state as being female, itself is a highly complex category constructed in contested sexual scientific discourses and other social practices' (Haraway, 1987:155)

Both Butler and Haraway take the position that the categories surrounding sex and gender are problematic and restrictive, and instead advocate for a world where these categories are broken down and challenged. I take this position in this thesis, following the cyborg manifesto's call to envisage a 'monstrous world without gender' (Haraway, 1987: 181), and avoiding thinking with universal, essentialising theories that create strict binaries between male and female. However, as Wilson, (2015) argues, in recent years, growing acceptance of the constructed nature of gender has led feminist theorists to be wary of including biology in their analyses. In Chapter Four, and in this thesis more broadly, I want to use these perspectives to think about gender alongside science and biology, and consider ways out of the dualisms presented when trying to think and write about sex and gender in the context of chronic pain.

2.4.2 Hormones, pheromones, genetics and sex

To do this, it is useful to look to how social scientists have begun to re-consider ideas of sex and gender. By examining the knowledge producing practices which have created the 'biological' concepts of sex, it is possible to trace the logics which have created the gender binary accepted by many today. For example, Roberts (2002, 2003) has written extensively about the history of endocrinology and the development of hormonal theories of sex difference. She describes how models of human gender emerged alongside the history of endocrinology. This history allows us to understand the development of models of sex which view 'male' and 'female' as static, binary, and opposite, concepts. Using Haraway (1988)'s concept of 'situated' knowledges, Roberts demonstrates that ideas of sexual difference produced through understandings of hormones are always an 'embodied fact' (Roberts, 2002). These embodied facts are produced historically and socially, and are dictated by the prevailing ideas of gender at a given time. By demonstrating how scientific discourses create ideas of sex, Roberts argues that while sex certainly incorporates biological aspects, these cannot be separated from the 'non-biological' aspects of the body. She calls for an understanding of sex that does not 'make determinist arguments about biological forces such as hormones' (Roberts, 2003: 207) and places an emphasis on looking to how knowledge about bodies is produced, in order to understand how sex is constructed.

Other feminist authors from within anthropology and sociology and science and technology studies (STS) have produced similar research, focusing in on the other perceived 'biological' aspects of sex. Sieben (2011) explores how pheromones have been produced in the scientific imaginary as being the biological basis for heterosexuality, despite limited evidence that these substances constitute a substantial part of human biochemistry. She focuses in on the example of knowledge produced around AND (androstadienone), a substance found primarily in young and middle-aged men thought to have pheromone-like effects. By looking into how ideas around pheromones are produced, and considering them through the lens of feminist theory, Sieben argues that it is possible to explore how scientific ideas can disrupt binary ideas of sex/gender and heterosexuality/homosexuality.

Similarly, Fujimura (2006) explored the research which led to ideas about the perceived genetic (and therefore static) basis of sex. By analysing the discovery of two key genes thought to dictate biological sex (sry and DAX-1) using a critical socio-material approach, Fujimura demonstrates that preconceived ideas of gender were deeply entrenched in the research designs that produced the discoveries of these genes. As such the processes which produced this research cannot be disentangled from already existing gendered 'performances'. For example, in mouse models, ideas around sexed behaviours were based on the 'aggressiveness' of the animal's behaviour. 'Male' mice were categorised according to whether they tried mate with other mice. This categorisation occurred alongside preconceived notions of what 'male' and 'female' bodies look like, for example through documenting the external presence of testes in the mice. Fujimara concludes that 'sex, even at the genetic level, is a socio-material process and product' (2006:76) and emphasises that these categories are not biological truths, but are rather constructed through many different, complex, genetic and social interactions.

2.4.3 Gut feminism and leaky concepts

Wilson (2015)'s *Gut Feminism* provides a space to think about the actual, embodied, experience of living under a diagnosis of chronic pain. I initially came to this text via readings within the anthropology of pharmaceuticals, but soon realised that it held importance to my thesis more broadly. This book aims to read biomedical data through a feminist lens, and challenge some of the ideas around 'biological orthodoxy' that exists both in biomedicine itself, but also within feminist theory (Wilson, 2015: 27).

The text itself discusses psychoanalytic theory, mental illness and the prescription of antidepressant pharmaceuticals to consider what biomedical and biological data could tell us about 'minded and bodily states' (Wilson, 2015: 1). While explicitly acknowledging the potential for harm that thinking only with biology can do, Wilson argues that biology is a lot more dynamic than both feminist scholars and biologists themselves would perhaps think. In the text, Wilson makes a call to put away the divisions between nature and culture – or, as Haraway (2003) would put it, adopt 'natureculture'. She argues that feminist scholars need to reject the 'antibiologism' present in much feminist theory and instead 'take biomedical data seriously, but not literally' (Wilson, 2015: 13). She argues we need to consider what thinking with biology can do for our analyses. In *Gut Feminism*, Wilson calls for a move back towards close readings of the body, encouraging us to explore 'entanglements of affects, ideations, nerves, agitation, sociality, pills, and synaptic biochemistry' (Wilson: 2015:1).

While acknowledging that thinking this way can be problematic, Wilson emphasises the importance of thinking beyond 'flat' notions of the body (Wilson, 2015: 66). She challenges what she perceives as a preconceived notion in feminist theory; thinking with bodily states is bad. Instead, she wonders what thinking with biology, and being curious about biomedical data and where it comes from, can do for feminist theory. She argues that 'feminist theory has presumed a kind of biology – a biology that is largely static and analytically useless'

(Wilson, 2015: 29). In this thesis, I have tried to get close to the biological narratives of pain that shaped my participants' understandings of their illnesses, while still being curious about the social and cultural reasons why my participants viewed their pain in this way. 'Taking biology seriously' (Wilson, 2015: 13) is something that I aim to pursue in this thesis. If we think about bodily processes and biology critically, as both a starting point and an end point, I ask what we can learn about women's experiences of living under a diagnosis of chronic pain?

The literature presented above demonstrates how it is possible to think about both sex and gender as being the product of various socio-scientific processes. Fujimura (2006) points to a term commonly used to in prokaryotic genetics to describe this: 'leaky'. She defines this leakiness in genetic terms; 'it means that things are not that stable. They are not something strongly determined' (Fujimura, 2006: 62). This leakiness is important when thinking about how we can understand the interplay between sex and gender. Shildrick, (1997:12) describes it as 'the very ground for a postmodernist feminist ethic', exploring in detail how the boundaries of 'femaleness' and 'female bodies' are not secure, and instead encouraging a move away from the essentialist views of reproductive potential and vulnerability which so often come alongside analyses of women's bodies.

This 'leakiness' has encouraged me to look to the bodies of my participants, without essentialising them. By doing so, I have been able to consider many of the issues of biology raised in this thesis, and especially in Chapter Six. This echoes the key argument made in Wilson's (2015) *Gut Feminism* – we need to take biology seriously, but not use it uncritically. In Chapter Six, I observe that the source of my participants' chronic pain was often viewed as residing somewhere deep in their (female) bodies and reproductive functions. By using perspectives around biology and gender, I hope to demonstrate that it is important to look at how people understand themselves, and their health, through a biological lens. This is why thinking with, and through, bodies is so important to the conclusions of this thesis.

2.5 The anthropology of pharmaceuticals, drugs and opioids

2.5.1 The anthropology of pharmaceuticals

The anthropology of pharmaceuticals is a well-established sub-discipline of medical anthropology. Prior to the 1980s, medical anthropologists were conspicuously absent from discussions around medication use. Literature published during the 1980s made a call for anthropologists to focus research on the use of pharmaceuticals as a matter of primary epistemic interest (Geest, 1984; Whyte and Van Der Geest, 1988). Medical anthropology's newfound interest in pharmaceuticals continued through the latter decades of the twentieth century. Whyte and Geest (1988) theorised that medicines have two distinctive qualities: they are physical substances, and they are believed to contain healing powers. They allow individuals to care for others, perform the sick role and communicate meaning (Nichter and Nordstrom, 1989; Vuckovic, 1999; Whyte, Geest and Hardon, 2002). These symbolic aspects of medicines formed much of the early literature produced within the anthropology of pharmaceuticals.

However, what is of importance to this thesis is the physicality of the pharmaceutical; it is a 'thing'. Geest, Whyte and Hardon (1996) argued for a 'biographical approach' to be used in order to understand this physicality. Throughout a pharmaceutical's metaphorical life-course, medicines pass through specific life stages – production and marketing, prescription, distribution, and finally consumption. After a medicine is consumed, its efficacy is determined. Further to the introduction of this 'biographical approach', Whyte, Geest and Hardon, (2002) published perhaps the most important book which understands medicines through this lens – *The Social Lives of Medicines*. It uses the 'social life' framework provided by Appadurai (1988), offering numerous examples of the interplay between the physical nature of medicines, how they move around, and their symbolic powers. This way of understanding medicines has led to the production of much interesting literature focused on how medicines are commodified, and how these medicines-as-commodities interact with global political economies (for examples see: Nichter, 2003; Ecks, 2005; Applbaum, 2006; Martin, 2006; Fisher, 2007). This has emerged alongside a biopolitical focus on the 'molecularisation' of social lives within political economies (Rose, 2001).

More recently, the anthropology of pharmaceuticals has been revisited and re-evaluated. In 'Fluid Drugs: Revisiting the Anthropology of Pharmaceuticals', Hardon and Sanabria (2017) emphasise that anthropologists can no longer legitimately draw distinctions between the biochemical and the social – pharmaceutical objects are never 'purely' chemical; they are made and remade in relation to context. They argue that to understand medicines, we need to work with the idea that bodies are not passive and think about 'matter flow'. Hardon and Sanabria (2017) draw from Ingold, (2012)'s work on material culture and how objects come to obtain meanings. They question what happens to the things we ingest as they move through the body. When considering the anthropology of pharmaceuticals, it is now important to align our thinking with broader trends in anthropology; we need to consider the interactions between human and non-human worlds.

2.5.2 The anthropology of drugs

Anthropologists first began to pay attention to addiction and illicit drug use in the 1970s, with an anthropology of addiction emerging alongside a perceived expansion of drug use in the West. What was previously deemed an area of sociological expertise, due to the notion of 'deviance', became an area of concern for anthropology (Singer, 2012). Alongside this, the HIV/AIDS pandemic also led to a public health focus on the links between IV drug use and HIV infection, therefore emphasising that understanding drug use falls under the domain of medical anthropology (Ibid.) This sub-discipline has provided important insights into the structural violence that often surrounds illicit drug use, and the public health value of harm-reduction strategies and safe supplies of drugs for the individuals who use them (Bourgois, Lettiere and Quesada, 1997; Bourgois, 2003; Bourgois and Schonberg, 2009; Wolfson-Stofko *et al.*, 2016).

Perhaps the most famous ethnography from within the anthropology of drugs is Bourgois and Schonberg, (2009)'s *Righteous Dopefiend.* It describes the lives of homeless heroin and crack users in San Francisco, exploring the material and social suffering participants faced, while also describing the 'moral economies of sharing' that often emerges in homeless communities (Bourgois, 1998). The authors use broader frameworks, such as structural violence, to describe the lives of participants in intense ethnographic detail. Importantly, they also use the text to emphasise the different public health interventions which have the potential to make a very real difference to the lives of people living with addiction.

Another text of particular note is Garcia (2010)'s *The Pastoral Clinic: Addiction and Dispossession Along the Rio Grande.* In this ethnography, Garcia (2010) chronicles the lives of heroin addicts in New Mexico, paying particular attention to the 'ordinariness', rather than the exceptionalism, of being addicted to opiates in her field site. She chronicles the intergenerational drug use which is characteristic of the women she worked with, contextualising this within a deep analysis of the importance of the history of the Rio Grande itself. When thinking about my own field site, this text encouraged me to pay more attention to the everyday aspects of taking different substances to manage chronic pain.

The anthropology of drugs can provide interesting insight into understanding how structural violence interacts with illicit drug use. However, importantly for this thesis, perspectives from the anthropology of pharmaceuticals seem to be conceptually distinct from the anthropology of drugs. The former takes a material-semiotic approach, thinking about the interactions between humans and objects in the context of global pharmaceutical networks. The latter looks at the motivations behind the use of illicit drugs, focusing deeply on structural violence as a causal mechanism.

2.5.3 Towards a molecular approach to opioids

Interestingly, most of the literature focused on the use of prescription opioids and other addictive pharmaceuticals has focused on how they are used for ‘recreational’ (or perhaps more accurately, non-clinically sanctioned) purposes. Much of this literature is unsurprisingly written about in the North American context. Because of this, this literature sits firmly within the anthropology of drugs. For example, Buer, Leukefeld and Havens, (2016) explore the various inequalities woven into the lives of women who use prescription drugs in Appalachia. Their research focuses on how prescription drugs are used outside of their originally intended purposes. They argue that the environmental and social contexts in which these drugs are consumed are core to understanding how prescription drugs are used for recreational purposes (Leukefeld *et al.*, 2007; Buer, Leukefeld and Havens, 2016). This literature focuses on how drugs are used to ‘feel better’, and looks to the kinds of traumatic life circumstances that might lead a person to use prescription drugs in this way.

Research focused specifically on prescription opioids has looked to concepts of ‘trust’ in the clinical relationship. Crowley-Matoka and True (2012) provide an ethnographic description of a US pain clinic for veterans. They describe the ambivalence and scepticism that doctors often feel towards pain patients, and the fear they feel around ‘getting played’ by ‘addicts’ when prescribing narcotic painkillers. The authors make the important point that in the US (and elsewhere), addiction is seen as a moral failing, regardless of the legality of the substance being taken.

Opioids, my original ethnographic object of interest, are a metaphorical space where the anthropology of pharmaceuticals collides with the anthropology of drugs. There are fragile boundaries between the categories of ‘legal’ and ‘illegal’ and ‘legitimate’ and ‘illegitimate’ that are important when considering prescription and non-prescription opioids. To think outside of these boundaries involves drawing from the anthropology of pharmaceuticals, to consider the molecules which constitute these drugs. Fig. 5 shows the near identical chemical composition of heroin (an illegal opioid) next to codeine (a prescription opioid). In reality, both of these substances are metabolised to morphine (another prescription opioid) in the body.

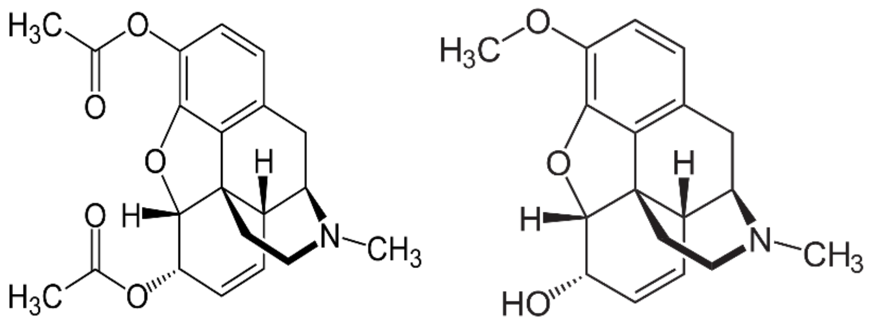

Figure 5: The molecular composition of heroin, an illegal opioid across much of the world (left), and codeine, a prescription opioid (right)

When considering the fragility of the boundaries between 'legal' and 'illegal' substances, it is important to consider the molecules that constitute them, and how they move through space and time. The distinctions can again be seen usefully through ideas around OATs (Opioid Agonist Treatments). These are pharmaceuticals used to treat addiction to opioids, but are also opioids themselves and thus have the potential for abuse and addiction. Gomart, (2002) describes the creation of methadone treatment in the latter half of the twentieth century, comparing the USA and in France. In this article, she details how the difference between methadone (an OAT) and heroin (an illegal opioid) is down to interpretation. Ideas around methadone and how it works vary between the USA and France; in the USA, methadone was seen as a corrective tool for addiction, in France it was seen as treating the underlying psychopathology of addiction.

Hansen and Skinner (2012) have considered the social meanings surrounding two different OATs: methadone and buprenorphine. These drugs are used in the treatment of opiate dependence in the US, but the authors identify the dimensions of class and race which surround the prescription and distribution of these medicines. They demonstrate how the use of buprenorphine is associated with the white middle classes, hidden in the doctor's office and framed as a treatment for a neurochemical imbalance. Methadone, on the other hand, is associated with government treatment projects for morally deficient addicts. The 'biopolitics of opioid analgesics' (Ibid., p.179) are exemplified, and the symbolic and political dimensions of pharmaceuticals and drugs emerge once more.

Here we can see that the lines between 'prescription' and 'non-prescription' can become increasingly blurred. It is for this reason that I have decided to use the word 'substances'[7] throughout this thesis, to cut across these categories. Throughout this thesis, I have become interested in how substances – whatever they were, and whatever legal status they had – were used to manage pain. The categories attached to any substance do not emerge a priori, but emerge during its biography. In Chapter Seven, I work from the premise that what is important to the way pain is managed using different substances is 'what works'. By using 'substances' as my epistemic starting point, I avoid some of the contradictions that occur by either thinking exclusively with the anthropology of pharmaceuticals, or the anthropology of drugs.

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[7] From the Latin *substantia* – something that stands under or grounds things (Robinson, 2021)

2.6 Biosociality and biocitizenship

2.6.1 Background to biosociality

Biosociality and biocitizenship are two interlinked but distinct concepts, important to understandings of how illness and diagnostic categories impact social life (Cooter, 2008). These concepts are heavily influenced by Foucauldian analyses of power. Both emerged from work focused on the epistemic consequences of the human genome project, with the bulk of the research on this theme emerging after the mid-1990s (Flower and Heath, 1993; Rabinow, 1996; Heath, Rapp and Taussig, 2004; Rose and Novas, 2005; Hacking, 2006; Cooter, 2008). Paul Rabinow (1996: 99) first used the term 'biosociality' to a prophetic end, stating:

> 'in the future, the new genetics will cease to be a biological metaphor for modern society and instead become a circulation network of identity terms and restriction loci'

From here, Rabinow argued that new forms of social life (or in his terms, biosociality) would emerge. These forms of social life would align people's genetics as the most important identifying factor about themselves – group identities would be created around ideas of a genetic truth which both dictated and predicted 'risk'. Rabinow anticipated that this 'biosociality' would begin to break down the boundaries between nature and culture, creating a 'risk society' where susceptibility to different illnesses and afflictions was inscribed deep in the genetics of individuals. Consequently, a person's genetics and other biological features would become an integral part of social identity.

Biosociality has become a very useful concept for medical anthropologists who have tried to understand the social groups that occur around different illness categories. In the last twenty years, work concerned with biosociality has attended more to the importance of different illness groups than to the forms of genetic risk envisaged by Rabinow in the 1990s. Medical anthropologists have looked to how groups of people navigate shared diagnoses, perhaps most notably written about in the case of HIV/AIDs (Marsland, 2012). More recently, Bradley (2021) has noted the importance of understanding lay concepts of biological identity formation when thinking about biosociality, through exploring how shared bodily experiences, such as compulsive hair pulling, create new biosocial relations between people.

2.6.2 Petryna's biocitizenship

In the early 2000s, the concept of biocitizenship emerged. This concept draws from much of the same foundational literature as biosociality, but instead explores how these biosocial processes fit into broader political economies. Petryna (2002)'s ethnography of post-disaster Chernobyl was the first text to explicitly introduce and apply the term biocitizenship. Petryna (2002:6) defines biocitizenship as being a 'selective access' to forms of state resources and aid, which were obtained through the evidencing of biological damage to people's bodies in the aftermath of the meltdown. In *Life Exposed*, Petryna explores how these claims to resources emerged in a very specific setting, describing the aftermath of the Chernobyl nuclear disaster as an 'anthropological shock' for Western Europe (Petryna, 2002:3). She demonstrates how ordinary citizens learned ways to engage with the sociomedical bureaucracies that emerged in the wake of the catastrophe. Medical and biological categories, which were created through evidencing of levels of exposure to certain amounts of radiation in the aftermath of the meltdown, became resources through which 'biologically damaged' citizens were able to make claims for state support.

She states:

> 'In Ukraine, where an emergent democracy is yoked to a harsh market transition, the damaged biology of a population has become the grounds for social membership and the basis for staking citizenship claims' (Petryna, 2002: 5)

In *Life Exposed*, Petryna writes very specifically about post-socialist decline and the changes to population management that occurred during and after the fall of the Soviet Union. The Chernobyl disaster allowed the Ukrainian government to 'develop a politics of national autonomy' (Petryna, 2002: 5) and assert certain forms of statehood through their administration and management of people's bodies in the aftermath of the disaster. This context cannot be directly applied to the contemporary situation in the North East. However, certain interesting parallels can be drawn between what is described above and the situation in North East England, especially regarding the need to demonstrate 'damaged biology' in order to access state resources. This is what I discuss at length in Chapter Eight.

2.6.3 Biocitizenship after Petryna

After Petryna, a body of work produced and influenced by Rose and Novas (2005) has expanded and complicated the notion of biocitizenship further. This literature aligns with the broader move in the social sciences towards considering life as becoming 'molecularised' (Rose, 2001). It focuses on how biological characteristics have become aligned with new forms of identity, and how these new forms of identity are, in turn, situated in broader 'global assemblages'. Rose and Novas (2005) argue that forms of citizenship are now dictated by engagement with market forces.

The concept of biocitizenship theorised by Rose and Novas (2005) is very specific, and is much narrower than the biosociality described by Rabinow (1996). When writing about biocitizenship, Rose and Novas are referring to the processes by which individuals within different biosocial groups advocate for access to treatments and resources. Alongside the broader notion of biocitizenship, other forms of related citizenship, such as genetic citizenship (Heath, Rapp and Taussig, 2004) and pharmaceutical citizenship (Ecks, 2005) have been theorised.

However, Rose and Novas' interpretation of biocitizenship has been criticised as being morally neutral and even reductionist in its approach to how biopower 'works' in society (Plows and Boddington, 2006; Raman and Tutton, 2010). When Rose and Novas (2005) write about biocitizenship, critics have argued that they have simply documented how it operates, rather than interrogating the power relations which surround it. In this thesis, I place emphasis on Petryna's view of biocitizenship when trying to understand the forms of biopower my participants were subject to.

2.7 Time and futurity in medical anthropology and disability studies

2.7.1 Subjunctivity, time and health

In this thesis, I am less interested in theorising about time per se, and more concerned with understanding how the experience of illness changes a person's orientation to time. In order to understand how concepts of the future and alternative temporalities are important to those living under a diagnosis of chronic pain, I have chosen to focus specifically on how medical anthropologists (rather than anthropologists more broadly) have thought and written about time. For example, Lochlann Jain, (2007) is referenced throughout this thesis. Her analysis of time in oncology demonstrates the importance of prognosis to understandings of the future; for those given a specific prognosis, embedded within it are multiple potential futures. More recently, Sakellariou, Nissen and Warren, (2021) in their close study of progressive motor neurone disease, have described how 'living in prognosis' is a lived experience. 'Living in prognosis' involves hopes and worries about what 'might' happen in coming days or years. This 'might' or 'potentiality' is crucial to understanding the final section of my thesis – 'The Future (?)'.

When thinking about chronic illnesses, getting a specific prognosis is much less common. As will be discussed extensively, diagnoses for contested illnesses like fibromyalgia, much less prognoses, are hard to come by. Still though, aspects of the uncertainty discussed above remain. A key anthropological text which informed the final section of my thesis is Whyte, (2002)'s *Subjectivity and subjunctivity: hoping for health in eastern Uganda.* This work is focused on the experiences of those living in Eastern Uganda who survived the HIV/AIDS pandemic of the 1980s. In this text, she employs the concept of subjunctivity, which emphasises how the chanciness that comes through living with a long-term illness is intrinsically linked to ideas about the future. Through this subjunctive mood, people actively engage with the various possibilities that could shape their lives. Thinking through a mood which describes events not certain to happen can help to consider the uncertainty, but also the possibilities for hope, that come alongside living with chronic illness.

Over the last 10 years, following Whyte's work on subjunctivity, medical anthropologists have explored the different ways understandings of the past, present, and future impact different health conditions. For example, Wolf-Meyer (2014) explores the kinds of temporal rhythms present in the formulas for treatment for narcolepsy and other sleep conditions. Without hope for cure, medications and medication regimens are what bring certainty and structure to the everyday. Further to this article, Wolf-Meyer and Callahan-Kapoor (2017) have used the concept of subjunctivity to understand more about how clinical understandings of 'prognosis' shape health behaviours and self-care strategies.

Similarly, Benton, Sangaramoorthy and Kalofonos (2017) have focused on the management of HIV/AIDS, through a multi-sited ethnography spanning multiple countries. They discuss the expectations placed upon patients to take up 'positive living' strategies. In their analysis, they show how their participants shape their lives, and the clock, around different treatment adherence strategies. They describe these 'positive living' strategies as being subject to neoliberal logics; rather having access to community-based care, their interlocutors were required to be self-sufficient and adhere to certain temporal expectations of self-care.

In very recent years, anthropologists have continued to engage with the concept of subjunctivity. For example, Sargent (2020) has drawn on work undertaken in Jordan with mothers faced with a pre-natal diagnoses of Down's syndrome. She emphasises that subjunctivity can be used to understand the many multiple meanings, feelings and futures that come alongside illness categories and diagnoses. Similarly, Hardin (2021) has used subjunctivity to explore healthy eating in Samoa. In this context, she argues that the idea of 'the vegetable' and the choice to eat it (or not) becomes a subjunctive symbol of both health, and wealth. Vegetables hold multiple meanings within them, and can represent the potential for health that certain actions can hold. Through the use of the concept of subjunctivity, medical anthropologists have explored the kinds of 'what ifs' and potentiality that emerge alongside treatments for long term health problems.

2.7.2 Disability studies, queer theory and crip time

Historically, disability studies has been an interdisciplinary endeavour that aims to represent and theorise the experiences of disabled people in society (Clare, 1999; Garland-Thomson, 2005, 2012; Garland-Thomson, 2005; Friedner and Weingarten, 2016; Davis and Sanchez, 2021). There is not enough space here to provide a full overview of this enormous body of literature, but a common theme within this work is to 'reimagine disability, to reveal how the storied quality of disability invents and reinvents the world we share' (Garland-Thomson, 2005a: 523). Similarly, this work is often aligned and intermingled with feminist theory, through a shared aim to 'rewrite oppressive social scripts' (Garland-Thomson, 2005b: 1567). Broadly speaking, disability studies is oriented around imagining different possibilities of being in the world, with disability at the forefront.

Similarly, queer theory has been broadly occupied with challenging the notions of normality which place heterosexuality as a 'default' position in society (Jagose, 1996). Its origins are grounded in the activism which arose around the HIV/AIDS epidemic of the 1980s and 1990s. However, 'queer theory' itself is not easy to define, and is arguably best considered as being an epistemology which challenges dominant discourses around what is 'normal' (Berlant and Warner, 1995).

This idea of normality is where questions of time and the future come into play for queer theory. For example, Edelman (2004)'s controversial *No Future: Queer Theory and the Death Drive* argues that our current understandings of politics and sociality are grounded in a 'reproductive futurism'. This 'reproductive futurism' is centred on the idea of heterosexual reproduction transmitting the current social order through the idealised image of 'the child'. Queer lives challenge this reproductive futurism, and Edelman argues for an abandonment of this projected future in favour of queer lives lived more radically in the present. As a counter to Edelman (2004)'s negative view of the possibilities of the future, Esteban Muñoz, (2009:1) argues that to be queer is to be 'imbued with potentiality' and as such the image of the 'queer' is a future-bound image. For Esteban Muñoz, queer theory needs to be infused with a utopian vision, which connects the historical and contemporary struggles faced by queer people with a political longing for a better future – queerness can 'allow us to see and feel beyond the quagmire of the present'.

With all this in mind, I want to turn to work done at the intersection of disability studies and queer theory. In *Crip Theory: Cultural Signs of Queerness and Disability,* McRuer, (2006) explicitly aligns the two strands of disability studies and queer theory. In it, McRuer introduces the concept of compulsory able-bodiedness, which states that the systems that produce disability are the same systems which place heterosexuality as the default sexual orientation. Through this assertion, explicit links between queerness and disability are forged and emphasised; the same assumptions of deviance are made about queer bodies as are made about disabled bodies. This deviance is temporal in nature. It is marked upon those who do not follow a life course which consists of birth, marriage, procreation, retirement and then death, in that order. By linking together the two bodies of literature briefly addressed above, McRuer (2006) explicitly aligns the oppression faced by those who are queer, disabled, or both.

Kafer, (2013) builds upon McRuer (2006) to draw together various strands from within queer theory and disability studies to understand how disabled people fit – or perhaps more accurately, do not fit – into traditional understandings of the human life course. In *Feminist, Queer, Crip* (Kafer, 2013) she argues that disability results in a reframing of temporality itself, resulting in the creation of something that she calls 'crip time'. This crip time can be best defined as a community-based temporality, which is implicitly understood by those who live with disabilities and within disability communities. It is about things taking more time, but also about the many complex barriers to 'doing things' that form the basis of much of what I write about in this thesis. In her own words, 'rather than bend disabled bodies and minds to meet the clock, crip time bends the clock to meet disabled bodies and minds' (Kafer, 2013:27).

While McRuer (2006)'s text was the first to explicitly link together disability studies and queer theory, Kafer's work aligns queer theory, disability studies and temporality. She does this through the following argument: neither queer people nor disabled people follow the typical life expected through 'compulsory able-bodiedness' (McRuer, 2006). Being queer or being disabled (or both) means that people may not have children, get married, or live to an old age. In the text, Kafer urges the reader to consider how being disabled changes a person's relation to time. Kafer argues that temporal categories are used to dictate and shape disability much in the same way that they have been used to 'other' queer relationships and ways of living. 'Queer time' has always been 'crip time' and vice versa. As such, playing close attention to these time categories can provide a useful space to think with when considering the links between queerness and disability.

Since *Feminist, Queer, Crip*, the concept of crip time has become central to how disability studies has understood disabled temporalities and futures. Samuels, (2017) argues that, amongst other things, 'crip time is time travel' – it extracts those who live in it from progressive time and places them into a 'wormhole', constantly moving backwards and forwards in time. Rather than this time travel being something negative, placed at odds with the rest of the world, *Feminist Queer Crip* allows us to view this version of time as something which opens multiple possibilities and new ways of being. This view is much the same as is presented by Esteban Muñoz (2009:1); it can insist on a 'potentiality or concrete possibility for another world'. It can allow for 'visions of elsewhere' (Kafer, 2013: 24) to be created.

It is important to note that the concept of crip time has been important not only to the form this thesis has taken, but also to the way I have understood my data. While doing my fieldwork, and writing up, I have come to understand that what is missing from this thesis is almost as important as the data I did gather. Here, I want to pause and recognise the cancelled, altered, and postponed plans which dominated much of my fieldwork. As I worked with my participants over my fieldwork period, I saw the operation of crip time in everyday life. It was then that I realised how important this concept would be to the representation of life with chronic pain in North East England.

2.7.3 From necessity and despair to possibility and hope

In 1978, Arthur Klienman, Leon Eisenberg and Byron Good published ‘Culture, Illness, and Care: Clinical Lessons from Anthropologic and Cross-Cultural Research’. This paper, which has influenced the work of both medical anthropologists and clinicians in the forty-five years since its publication, suggests eight simple questions for clinicians to ask when trying to understand a person’s illness narrative:

1. What do you think has caused your problem?
2. Why do you think it started when it did?
3. What do you think your sickness does to you? How does it work?
4. How severe is your sickness? Will it have a short or long course?
5. What kind of treatment do you think you should receive?
6. What are the most important results you hope to receive from this treatment?
7. What are the chief problems your sickness has caused for you?
8. What do you fear most about your sickness?

(Kleinman, Eisenberg and Good, 1978)

Here, I want to pay attention to questions four, six and eight. These three questions are all future-facing, and encapsulate well the unknowns of hope, despair and worry which emerge alongside unknown illness. Kleinman (1988) himself warned against the kinds of ‘demoralisation’ – the opposite of hope – that can occur when a patient is faced with a long-term illness. Barnard, (1995) argues that for those who are chronically ill and/or disabled the boundaries that exist between hope and despair are ever more prominent. This prominence creates an ‘existential paradox’, requiring a person to constantly work around, and defy, the limitations they experience. By defying these limitations, a person engages with the possibilities of how life *could* be. Chesla, (2005) argues that the ideas of necessity and despair which are almost ubiquitous to the experience of chronic illness have a more positive reflection: possibility and hope. For Chesla, (2005:374) ‘hope, as a way out of suffering, is thought of in the future’.

2.7.4 Biopolitics and hope

Novas (2006) has provided a biopolitical framework for understanding how both individuals and groups that live under certain diagnoses understand and experience hope. In his analysis of different patient advocacy groups for those affected by different genetic conditions, Novas discusses how hope is ‘materialised through a range of social practices’ (Novas, 2006: 289). He makes the astute observation that the language of hope is often the same language used to describe scientific progress; pushing past barriers, finding new frontiers and overcoming obstacles. Waldby (2000) has argued that this future-facing drive leads to these groups becoming implicated in the production of ‘biovalue’ for various multinational organisations.

Here I want to contend that Novas’ critical stance on the ways biopolitics and support groups can collide is valid. The problems that arise when responsibility for care is placed onto individuals and groups, and the issues that can emerge from the need to see chronic illnesses through a genetic and/or biological lens have been central to this thesis. However, what I am interested in here is how people in different illness communities experience hope. He describes this as follows:

> ‘To have or to ‘live in’ hope means to take an active stance towards the future so that the possibilities and potentiality inherent in the present may be rendered achievable. Hope is both individual and collective: it ties together personal biographies, collective hopes for a better future, and broader social, economic and political processes. Hope involves interplay between the present and the future, and requires individual and collective activity to enable its realization, it is congruent with the formulation of strategies. To enable hope requires the coordination and management of the conduct of individuals and groups so that a particular future may come into being.’ (Novas, 2006: 291)

Further to Novas’ work, Eaves, Nichter and Ritenbaugh, (2016) have written on the experience of living with chronic pain and hoping for relief. I have previously mentioned this text while writing about pain, but here I look to what it can tell us about hope. In the text, the authors explore the kinds of paradoxes that come alongside living with pain, and explore multiple ‘ways of hoping’ as being a form of ‘tacit’ knowledge. These ‘ways of hoping’ include: realistic hope, utopian hope, wishful hope, existential hope and hope that is linked with faith (either in religion or biomedicine). By categorising hope like this, they emphasise that finding different forms of hope is part of learning to live with chronic illness. Importantly, they see hope as vulnerability, which again is oriented to the future. They suggest that ‘multiple ways of hoping enable sufferers to adapt to contingencies and experiences such that they can remain hopeful and open to the possibility of aid on the horizon’ (Eaves *et al*., 2016: 17). For both Novas (2006) and Eaves (2016) the word possibility is of utmost importance. These ‘time words’: subjunctivity, anticipation, possibility and potentiality, are central to what will be discussed throughout this thesis. They are especially pertinent to ‘the future(?)’, where I discuss ideas about chronic illness and the possibility of a better world.

2.8 Conclusion

This chapter has provided an overview of the key theoretical threads important to understanding the ethnographic chapters of this thesis. I have introduced my epistemic position – that of a ‘critical feminist disability anthropologist’. From here, I described how this position influenced the kind ‘citational politics’ (Ahmed, 2017: 15) I have engaged with throughout this thesis. After this, I introduced my key theoretical threads in turn: pain and violence, key perspectives on diagnosis, key perspectives on gender and sex, the anthropology of pharmaceuticals, drugs and opioids, biosociality and biocitizenship, and ideas about time and futurity in medical anthropology and disability studies. Throughout, I have attempted to emphasise the theoretical links that exist between these key concepts. I hope these links become further enriched by the ethnographic chapters which follow.

SECTION ONE: THE PAST, OR WHAT HAPPENED BEFORE

3 Chapter Three: Trauma and Violence in North East England

> ‘My back… it’s like someone has placed a heavy stone slab on it for a couple of days then taken it off’
> - Ella, describing her back pain to me
>
> ‘My body screams at me, wrapped in barbed wire, in baths of bubbling hot oil, ice being poured all over me, Lilliputians fighting their wars on my limbs, blunt red-hot pokers piercing through my limbs. I’ve been unable to wear trousers for months, the fabric on my legs and varying pressure, the seams, the stitching, the texture, the fabric, my word, pure torture…’
> - Facebook Post written by Thelma, shared with me
>
> ‘My body is going on strike’
> - Comment made during a support group conversation
>
> ‘My body is burning… it feels like there’s someone in there with a blowtorch’
> - Comment made during a support group conversation

The above quotes were shared with me during various conversations that occurred across the months I spent doing fieldwork. The women who took part in my research often talked about their pain using metaphors of violence, protest, and assault. They speak of heavy stone slabs, blow torches, vats of hot oil. Through these words, the body and its constituent parts are made alive, with their own agency and decision-making capacity. Bodies are out of control: on strike, screaming at the sufferer, victims of an unidentifiable assailant.

This chapter introduces the complex conversations about violence, trauma and chronic pain that are important to this thesis. Understandings of violent events, trauma, and the connections that exist between the mind and the body are central to understanding the lives of my participants. Often, trauma is viewed as being something – an event – which occurs in the past and directly influences the form the present takes. However, for the women who took part in my fieldwork, links between past and present experiences of violence are tangled. This chapter focuses on these trauma narratives, considering how they diffuse into understandings of the aetiology of chronic pain. In the medical literature that surrounds this topic, explicit links are drawn between past traumatic life events and the development of chronic pain in the present (Houdenhove, Luyten and Egle, 2008; Beck and Clapp, 2011; Beard and Aldington, 2012; Craig *et al.*, 2020). However, this chapter does not focus on causal models, instead contemplating how violence is interwoven into the everyday experience of chronic pain, and how this violence can be traced back to broader structural sources (Das, 2007, 2008).

In what follows, I apply the anthropological perspectives on violence I presented in the literature review, namely the collective works of Arthur Kleinman, Veena Das, and Margaret Lock (Kleinman, Das and Lock, 1997; Das et al., 2000; Das, Kleinman and Lock, 2001; Das, 2007) alongside the concept of structural violence (Farmer, 1997, 2004a). Using ethnographic examples, I demonstrate that the folding of violence into the everyday lives of my participants is inherently structural. The violence experienced by the women discussed in this chapter can be understood as being demonstrative of broader structural inequalities: the early death of loved ones from non-communicable diseases, gender-based violence, and state neglect of health and social care services.

The stories of what participants experienced will not be the focus of this chapter. I could, with ease, recount many stories of the unimaginable violence many participants experienced and continued to live with in their everyday lives. However, writing on violence presents many ethical issues, including concerns of voyeurism (Jacobs, 2004) and academic sensationalism (Bringedal Houge, 2022). Therefore, I take the position that detailing my participants' violent experiences is neither appropriate nor particularly useful to what I want to write about.

Instead, I will explore how experiencing violence shapes life under a diagnosis of chronic pain. Most of the women who took part in my research had experienced forms of interpersonal violence throughout their lives, alongside other experiences which could be easily classified as 'traumatic'. The purpose of this chapter is to discuss the nuance that surrounded how people viewed what had happened to them in the context of their chronic pain diagnosis. I analyse how my participants understood the things that happened to them in the past, and continue to happen to them in the present, exploring the tensions that emerge when a specific aetiology for complex chronic pain is sought. In this chapter, I argue that the pain my participants experienced was often maintained by structural forces.

What I hope to demonstrate in this chapter is that links between violence and pain are not experienced in the linear sense often imagined in the biomedical and psychological literature on chronic pain. Instead, they are deeply entwined not only in people's histories, but in the reality of their lives in the present, too. These cumulative violent experiences serve to influence how people live every day. Environments that are generative of domestic abuse, sexual violence, and poverty, etc., are also generative of chronic pain, and as such a directly causal view of the links between these things does not fully encompass the experiences of those who live with pain day to day. In this chapter, I hope to present a way of thinking that bridges the links between past and present, considering how pain is produced in the everyday, but is viewed through the lens of the past.

3.1 Everyday structural violence in North East England

Walking around Mountainhead with Thelma 16.6.21

It was a hot day in June, and I was due to meet Thelma for a dog walk. I parked up and saw Thelma and her puppy, Princess, approach the village hall. Princess was lolloping alongside Thelma, who was in her electric wheelchair. I said hi to Thelma and Princess in turn, and we set off on our walk.

I let Thelma lead the way as she knew what would be accessible for her, and suitable for the puppy. We walked to the dropped kerb so we could both cross the road, and we talked about how difficult access to the pavement was for her, she has to move much further than other people have to be able to cross the road. She told me how she had sold her house to pay for the wheelchair, as the council hadn't been willing to fund the one she wanted. We were walking in the shade at this point and I was glad for a break from the sun, already. We crossed a drain embedded in the pavement and I saw that Thelma flinched a little as she went over the bumpy ground, telling me she felt shooting pains in her legs when moving across an uneven surface.

We nipped down a back road, so we didn't have to go on the pavement anymore, and Thelma looked much more comfortable. The road backed onto a field with a view down towards some fields. When I come to Mountainhead, I always forget that it is quite rural, as the centre of the village is almost entirely concrete.

Princess was pulling at the lead, and Thelma told me about the apprehension she feels about going to places such as fields and possibly getting stuck. She knows there are people about who could help her, but I sensed a sadness that she couldn't just nip into the field and let the dog off lead to run without fear of being stranded. As we moved along the road, she expressed the disorientation she often feels; 'I've lived here all me life… but I still get lost navigating the pavements', she said.

Princess got stuck round an electricity pole and we paused to untangle her. She has a huge amount of energy, running back and forth on her lead and wanting to smell absolutely everything. Thelma talked about how dogs are important, especially when you have chronic pain – they help you structure your life and force you out of bed. Even though the dog is a lot of work for Thelma, she's worth it for her and her girls. At this point we had moved back onto the pavement. It had become very narrow, so I walked behind to allow us all to fit through. We stopped to rest, and Thelma gave Princess some water from a portable bowl, the puppy lapping up the cool water. It was getting very hot.

We were walking out of the village now, and I asked how Thelma understood the kinds of things that went on in her local area. She chuckled and told me that when something happens in Mountainhead people talk about it forever, giving me the example of how, on the 1st January 2000, a guy had pulled a gun on his girlfriend. It was all people talked about for 3 years. All the gossip is part of the reason she would feel uncomfortable self-medicating her chronic pain, or talking too openly about her current medications. People would either judge her, report her to social services, or try and rob her.

A man walked past us and stared Thelma down, hard. After he passed, she told me that he didn't like her at all (which I had inferred from the looks they gave each other). It turned out the man was an ex of one of her friends, who he had been extremely abusive towards. Thelma had supported her friend to leave her partner, and since then there had been a huge amount of animosity between them. She told me, flatly, how domestic violence is rife in this community. She described how the area had one of the highest rates of domestic violence in the country, alongside some of the highest rates of autism too – both facts which applied to her family. She began to tell me about her ex-husband, how he hadn't always been violent, and that it had started very slowly. We were interrupted by someone walking past us and stopping to stroke the puppy, so the conversation stopped there.

We were moving up a hill, a slow but steady incline. I felt distinctly out of breath. We weren't talking much, and I could hear the whirr of Thelma's wheelchair as we moved up in the hill. We reached the summit, near to where Thelma grew up. There was a view across the valley; dotted clusters of housing estates and green fields. She pointed out to me, again, why dropped kerbs are so important as we searched for somewhere to dismount the curb. 'It takes me 3 times as long to do anything', she said.

We were now walking towards a place called North Moor, and she pointed out how bad the dropped kerbs were in this particular area. She warned me that we were going past where her ex-husband used to live, and that she was going to feel tense doing so, despite him not having lived there for years. We walked past some of the main shops and she pointed out one of the nurseries she wanted to send her kids to but couldn't because they did not have proper wheelchair access. There was a cluster of shops which represented the centre of this village: a corner shop, a betting shop, a fish and chip shop. By these shops, there were two cars parked on the pavement *with not much space between them. Luckily, before we reached this blockage, one of them moved and Thelma and her electric wheelchair were able to pass through as once again we searched for a dropped kerb.*

As we walked, I let Thelma talk about whatever was on her mind. She mentioned to me the suicidal thoughts CRPS [her diagnosis] makes her feel, and how they 'scare the shit out of her'. In her view, the only way to stop the pain she feels is by dying, and that thought intrudes her mind very often. 'But' she said to me 'no one will look after the kids like I do'. She talked about this, me listening, as we began to walk through a park. There was a strong smell of marijuana, and a run-down children's playground looming head of us. At the sight of the playground, we began talking about her ex again. She told me that they have tried to co-parent but it just doesn't work. Every time he gets access to the children, the manipulation games which characterised their relationship start up again.

In the middle of this conversation Thelma's wheelchair screeched to a halt. She had seen a bumblebee on the floor in the middle of the path we were moving down. It was hot, and the bee was struggling. 'We need to give this bee some water' she said, softly. Our walk then quickly turned into a bee rescue mission. I lifted the bee onto a leaf and placed it into the shade on the side of the path. Thelma handed me her water bottle so I could create a place for the bee to drink from. When satisfied the bee would recover, we moved on.

We moved out from the park. Thelma looked at the houses around us and told me that 'everyone round here has depression and anxiety – I just mask mine well because I don't have a choice'. Because of her health conditions antidepressants are off the cards, so I asked if she had ever sought counselling. We had a bit of a laugh about the concept of Cognitive Behavioural Therapy (CBT) for victims of violence like herself — it just seems like being offered nothing. She told me about the way specialist domestic violence counsellors have reacted to some of the things she had experienced and about getting CBT for postnatal depression. When describing the judgement she felt as a disabled mother to her therapist, the therapist had told her that none of their friends would ever judge her for being a disabled mother, so Thelma shouldn't worry about any judgement. 'But this therapist… that's middle-class, from a middle-class perspective, not lower-class', Thelma observed to me.

We began our descent down the hill again. I could see County Durham stretching out before us, wind turbines on the horizon. We walked past the house Thelma's grandmother used to live in, and to avoid the dropped kerb issue we just gave up and started moving on the road. We stopped to say hi to the lollipop lady, and made our way, slowly but steadily, back to Mountainhead.

The walk I went on with Thelma demonstrates the ways violence is 'folded' into everyday actions and relationships between people (Das, 2007). As we walked Princess, we travelled around different places in the local area, many of which had some form of physic meaning, or memory, attached to them. The importance of place to life under diagnosis will be discussed in Chapter Eight, through Proudfoot (2019)'s concept of the traumatic landscape. However, the point to draw from the above vignette is that Thelma made connections between where she lived and the things that had happened to her throughout her life. Furthermore, these connections were linked to her experience of chronic pain, and of being a chronically ill mother. As outlined in my literature review, anthropologists have often understood violence and its consequences using these frameworks. These frameworks can certainly be applied to the experiences of the women who took part in my fieldwork. As much as being a part of their pasts, violence was also infused in how they moved through the world in the everyday. However, in this chapter I argue that structural violence is the most useful way to understand the experiences of my participants.

How, then, does structural violence serve to generate and maintain chronic pain states? Good *et al.* (1992:3), when writing on the subject, argue that chronic pain 'highlights the fault lines in society' and can serve to further emphasise already existing health and economic inequalities. Rather than focusing on how trauma can lead directly to the development of chronic pain, it is important to understand how trauma and violence is often enmeshed in the everyday lives of those living under a diagnosis of chronic pain. Throughout my fieldwork, I found that people diagnosed with chronic pain were often subject to a two-fold process. First, they were often at the 'sharp end' of violent structures (political, gendered and classed) which contribute more broadly to the poor health outcomes that continue to plague North East England. These structures form a theme that underlies many of the topics discussed in this thesis and will be considered at length as it progresses.

Second, and importantly to this chapter, the violent experiences that constituted people's life histories and everyday experience of the world were often given as the exclusive cause of chronic pain by medical professionals. Causal links were drawn by medical professionals between, for example, experiences of domestic violence and chronic pain. During interviews, several participants told me sceptically that they had been told that their pain was caused by experiences in their pasts. As a consequence, they were wary of disclosing experiences of domestic violence to health professionals. As will be seen throughout this chapter, participants were not entirely resistant to the idea that previous life experiences might be involved in their pain. However, they were sceptical of direct links being drawn, especially as these links often resulted in the ongoing disbelief or dismissal of bodily symptoms as being 'all in your head', or purely psychosomatic. I heard many stories, some presented in this thesis, of health problems which required urgent medical attention or investigation being abstracted back to past experiences of 'trauma'.

Here, I want to emphasise again that the violence experienced by my participants was undoubtedly structural in nature. Violent experiences dictated the everyday as much as it constituted things that happened to people in the past. Below, I discuss a conversation which occurred at a support group I attended, with details changed to avoid any potential identifying details:

M.H.P.S.G, October 2021

I walked in, a little late as I had got lost on the way, Becky, the group leader, and Peggy, an older lady, were talking in quiet voices. Becky looked upset. I froze a bit as if I could tell what was coming. I sat down to an eerie silence. Becky began to tell the group about 'something bad' that had happened to her 20 years ago, and how it was all coming to a head now. She had been asked to report the 'bad thing' to the police after speaking to a therapist about the impact it had had on her. She never mentioned specifically what had happened, but she said she saw no point in reporting it now, other than to perhaps protect other people from her abuser. She told us the story in fragments; they had been in a relationship at the time, he had been abusive to her throughout. Most importantly, the police had done nothing. 'He was kicking the shit out of me at the bus stop' she told the group, tears in her eyes, 'and I rang the police and they did nothing, I was screaming down the phone at them'. She told us how conflicted she was about reporting what had happened to her due to how little she trusted the police – the perpetrator was well-known to her, the local community, and the authorities. He had been arrested so *many times, and was still arrested regularly, but never ended up going to jail. She told us another fragment of a story; due to his behaviour, her little girl was taken off her by social services. She told social services about him, and they rang the police to see if they could help. Apparently, the policeman who had been spoken to had chuckled down the phone after hearing the man's name and said 'you'll need the army to deal with him' before hanging up. Just last week he had been caught chasing someone around the local area with a chainsaw. Peggy, who was stood up next to Becky, leaning on her crutch, shook her head and said 'he's dangerous, him' as her response to the entire story. She clearly knew the man well and seemed apprehensive about even talking about him in this setting.*

Without wanting to interrupt a moment that was clearly important to Becky, I waited a while before saying that she was not alone. I told her that I had heard so many stories during my fieldwork of things like this. Becky looked me in the eyes and clearly identified 'what happened to her' as the source and cause of her chronic pain, alongside saying that the stress of all the emotional pain resurfacing now was making her symptoms much worse.

The conversation at the group was centred around Becky confessing something traumatic that had happened in her past. But the event(s) described in the above passage were not isolated – they were interlinked in deeply structural ways. It was not that 'what had happened to her' was represented as a static event in her past which was identified as the cause of her chronic pain. Rather, the (lack of) police response and the inability of state power to prevent, or punish, the violence which had been inflicted upon her and her children was part of the story she told the group.

In her own short account, Becky's experiences spanned across two decades, with the fear she felt about the power her abuser held over her and her community still ever-present in our conversation. The traumas experienced by Becky were as much structural as they were interpersonal. When Becky experienced one-on-one physical gendered violence, for example her ex-partner 'kicking the shit out of her' at a bus stop, she also experienced structural violence. When reported, the police had done nothing to intervene in the violence and had in fact admitted they were unable, or unwilling, to help Becky with the resources they had.

In the present day, this meant Becky felt hopeless in the pursuit of justice. The perpetrator of the violence committed against her was well known in the local community, to the point where they could be declared by other group members as 'dangerous'. This example demonstrates the kind of 'folding' Das (2007) describes when writing about how extraordinary acts of violence become a mundane part of the everyday – the scene I describe above was not met with shock by the members of the support group, but rather a sad acceptance. However, it was structural forces that prevented Becky from feeling like she would be able to access justice for what had been committed against her. When she aligned what had happened to her with her chronic pain, I felt that she was trying to emphasise to me the extreme impact these experiences had had on her life. This impact was ongoing, and not simply relegated to the past.

3.2 The links between trauma, violence and chronic pain

As discussed in my literature review, critical theorists have written extensively about the concept of 'pain' (Scarry, 1985; Morris, 1991). Scarry (1985)'s The Body in Pain explicitly aligns the experience of pain with the power that violent acts can hold. She argues that because pain is ineffable, it is also political – the language used to describe pain (or not) can be co-opted politically. This is most notably seen through Scarry's analysis of the use of torture by intelligence agencies. The difficulties that emerge when attempting to communicate pain are, to Scarry, central to the power relations which emerge between a torturer and a victim. When in pain, a person's world shrinks down and language fails them. As a consequence, power dynamics are created between those in pain and those who are able to inflict it.

However, the quotes presented at the start of this chapter provide a counter to Scarry's description of the epistemic ambiguity of pain – pain is indeed describable, and is communicated through the language of violence itself. The phrase 'bubbling vats of hot oil' used by Thelma in her post on Facebook invokes some form of empathy, creating a metaphor in the reader's mind which communicates at least something about that experience of the pain and what it felt like. Writing on agency and pain, Asad (2000), argues along these lines. By using metaphors to describe pain, experience becomes structured – Asad states that pain does not destroy language at all, instead it becomes real through the telling of stories. If we could not recognise another's pain through language, then it would be difficult to understand the justification for, for example, torture. In other words, when pain is spoken about, it becomes public rhetoric and can be used accordingly. In Asad's understanding, describing pain is fundamentally concerned with how this pain is communicated to others.

Although placed theoretically at odds with each other, both Scarry (1985)'s and Asad (2000)'s positions accept that there are complex links between experiences of trauma and chronic pain states. Scarry draws explicit links between traumatic experiences and pain, while Asad (2000: 43) states 'What a subject experiences as painful, and how, are not only culturally and physically mediated, they are themselves modes of living painful relations'. These ideas are represented extensively in the psychological and medical literature, with many studies attempting to unearth the links – both biological and psychosomatic – between traumatic experiences and persistent pain (Loeser, 1991; Houdenhove, Luyten and Egle, 2008; Young Casey *et al.*, 2008; Beck and Clapp, 2011; Beard and Aldington, 2012; Craig *et al.*, 2020). Alongside this, there are also several popular science books which bring ideas about the somatisation of mental distress into bodily pain and suffering into the public sphere, and furthermore the public psyche (Van der Kolk, 2014; Maté, 2019). What can be seen, through both theoretical and empirical perspectives on trauma and pain, is a clear causal link drawn between what has happened to someone in the past, and what they experience in the present.

3.3 Trauma as experience

The rest of this chapter will consider that often there was no single direct causal link between the pain my participants experienced every day, and what had happened to them in the past. As mentioned earlier, when attending medical appointments, links were often drawn between a person's prior histories of experiencing violence and their chronic pain. As Bourke, (2012) argues, this pattern does not exist in isolation, but can be contextualised by looking to the historical discourses which have existed around women who experience both violence and pain. These gendered elements are important and will be discussed in more detail later in this thesis. In this chapter, I want to focus on the way my participants understood, and sometimes challenged, these discourses.

Becky, whose experiences were discussed above, sometimes suggested to me that she thought the violent experiences in her past were what caused her pain. These suggestions most often occurred when we talked about things that had happened to her in the past. However, other times, we discussed other potential causes. The most frequent explanation I heard was that that she thought she had been living with undiagnosed lupus for years. Through these multiple narratives, I argue that multiple causes of pain existed in my participants' pasts, and that these causes extended deeply into their everyday lives.

Many participants chose to resist or question the narratives which linked up 'bad things' in their past with the development of chronic pain. When Thelma told me about her abusive ex-husband in more detail, she told me that when she met him, she already had chronic pain. In fact, she believed that the chronic pain made her vulnerable to exploitation by him. *'I already had CRPS when I met him'*, she said to me, but *'having him beat the shit out of me every day certainly didn't help with my pain'*. This kind of nuance is important as it helps to blur the lines and challenge some of the ideas of causality which have placed trauma and violence firmly into my participants' pasts.

To give more nuance to the idea of trauma as experience, rather than direct cause, I will now use data from interviews and excerpts from field notes to demonstrate how participants understood their own traumatic experiences in relation to their chronic pain. Multiple illness narratives around the aetiology and maintenance of pain were common, and these narratives were often simultaneously biomedical and social. Through this lens, traumatic experiences were certainly interweaved into pasts, but were also part of how people navigated through the world in the everyday.

I spoke at length about these questions of causality with one of my participants, Andrea. During the time we got to know each other, we spoke over Zoom. Andrea worked in children's services and was often busy, so I would try and catch her before work, on her lunch break, or on the odd day off. The first time we spoke, she explained all the physical problems (namely a slipped disk in her back) which had led to her developing chronic pain and finally being diagnosed with fibromyalgia. Later, during another interview, we talked about potential other causes of her chronic pain:

'when I look back at it… I don't know if it was the loss of my dad? The shock, because he went quick. At the time, I ended up having a bit of a breakdown, but a few years later… I had a breakdown because I lost my mother-in-law, and then my dad… it was all so quick. They were both quite young. And then I looked after my husband's dad… but then I think to myself. I don't know whether it was the shock to my body? He was my life, he was everything. When I look back, I think that's when a lot of the pain did start happening, but then I wonder if I'm just thinking that? I know… I can put it down to when I had my accident, but when I look at my sinus pain, my IBS…. Beforehand I was so fit. I was a dancer, I was doing everything, I bought the kids up, we'd be running, walking up the moors. And then when I lost my dad I just totally, I lost… I didn't want to be here. I wanted him back. I don't know what it was, whether it was a shock to the system, whether it triggered something. I can't put my finger on what's done it.'

Andrea's account of losing her father and its connection to her pain demonstrates again the kind of debates that occurred in the minds of my participants about what 'caused' their pain. In this excerpt, Andrea places both the accident she had and multiple bereavements she experienced as influencing her life under diagnosis. However, any discussion of the cause of her pain was centred around her biology – she spoke of ‘shocks’ to her system triggering some underlying abnormality in her body.

Another participant, Ivy, whose diagnosis history constitutes the introduction to Chapter Four, had a similar experience. Her illness narrative placed a flu infection as the origin of her fibromyalgia, but as we got to know each other over Zoom during the 2021 Covid-19 lockdown, we spoke more about the grief she felt about the loss of her husband, John. He had died after a protracted stay in a care home, after being diagnosed with Lewy-Body dementia a few years before.

Ivy: ‘When he died… it was like losing him again. And I don’t think that’s helped, with how my pain has been. Because with John dying, and then my mam. Yes, he had the dementia and he had been in care. And he’d been in care for 6.5/7 years, but he was fit. It was a fall… he had a bleed to the brain. After the fall, they couldn’t even X-ray him. Within a couple of days he was blind so obviously he’d had a haemorrhage. So he just gave up. But my mum was dying of cancer at the time, and she died two months later. And John’s sister, she died two days before John. The day that John died, I’d come home to get changed. And the phone went, and it was John’s niece. She said ‘I’ve been trying to get a hold of you, me mam died on Thursday. And I said ‘I can’t believe this, your uncle John hasn’t got long to live as well’. She said ‘well, I din’t wanna leave a message’. And that was Thursday, John died on the Sunday. He was the last of 5 siblings in the end. They had Hannah’s funeral one week, and John’s the next. As I say, my mum died in the December. I felt as though everything had caved in around me. I had counselling, but I felt as though my fibro during that time was horrendous’

Lucy: ‘I don’t understand how anyone would manage that level of loss without feeling awful, to be honest’

Ivy: ‘everything seems to be heightened. The pains. At the time, it wasn’t just. Normally its one area at a time, but. It was everywhere. When I was feeling really low and depressed you think, is it just because I am thinking about it more?’

Lucy: ‘what do you think?’

Ivy: ‘I really don’t know. There are some days when I’m not thinking about it and it's there, and there are other days… specially now when you’re sitting around bored. I’m sick of watching box sets. When you are down and low, it does seem to heighten everything.’

Here again it is possible to see how understandings of pain are linked up with experiences of extreme grief. However, what is important to note is that Ivy sees the bereavements she experienced as exacerbating already existing pain, and ‘heightening’ her fibromyalgia symptoms. Prior to her marriage to John, she had been married to an abusive man, the father of her two children. When she told me the story of how the abuse started, and how it manifested, I asked her if she thought this linked to her pain at all. She paused before telling me that in this case she thought *‘trauma accelerates things, doesn’t it’*, before telling me again the story of the flu which had triggered off her fibromyalgia symptoms and which she placed as the ‘starting point’ in her diagnosis history. For Ivy, it is very clear that feelings of grief, sadness, and the experience of abuse, magnified the chronic pain symptoms she felt, but certainly did not cause them.

Similarly, Chloe, a 24-year-old woman from near Sunderland, explicitly refuted the idea that her fibromyalgia was trauma-based. During one of our first conversations, we discussed this at length. She had been told that fibromyalgia typically had a basis in a traumatic experience by one of her doctors, and due to this fact doubted that her diagnosis was correct, stating that *'fibromyalgia is meant to be trauma-based, but me… I've had the best life ever'*. As we got to know each other better, I discovered that she had, objectively, faced a lot of adversity in her life. A few months after she had told me she thought her diagnosis of fibromyalgia was incorrect, I decided to ask about the topic again to see if anything had changed. She maintained that for her, her experiences did not constitute traumatic ones. *'Death?'*, she said, '*sure, but abuse or anything like that, no'*. For Chloe, the experiences which constituted her formative years had no bearing on her diagnosis of fibromyalgia. She had a suspicion that her chronic pain was caused by something physical, or genetic. Many times she mentioned to me that she thought she had EDS (Ehlers Danlos Syndrome – a genetic condition) rather than her chronic pain being caused by fibro.

However, some participants did recognise the impact that experiences they had as children had on their pain as an adult. Jennifer, who's diagnosis history will be discussed in the next chapter, was diagnosed with a painful genetic condition in adulthood. After diagnosis, she had retrained as a counsellor – a job she could do while sitting down. Her background in psychology led to lots of interesting conversations between us about the origins of her chronic pain.

Jennifer: 'It's a vicious circle isn't it, if you're in pain your mood is not so great, if you're mood's not so great, you're also in pain.'

Lucy: 'do you think your background in counselling helps you manage that?'

Jennifer: 'no, I think it probably does. Absolutely yeah yeah. I've read some incredible books about, you know, the mind-body connection and… one of me favourites is called 'the body keeps the score'.

Lucy: 'I thought you might mention that!'

Jennifer: 'it's like, a bible isn't it. Gabor Maté too, 'When the body says no'. That's an incredible book as well. Some of it, as well, some of it makes sense. The adversity that I had when I was growing up, as well. Me mum and dad, they had a violent relationship with each other, when Jen and me were just little. You know, has that had a knock-on effect? I think what you've said is right though, that background reading and understanding—Christ! All this stuff could have affected me to be the way I am.'

Jennifer was one participant who did specifically link up experiences in her childhood to the chronic pain she experienced in her everyday life. When thinking back to the violence in her childhood, she wondered out loud to me whether these experiences had a 'knock-on effect' on her health in adulthood. Later in the year, we met up near her house to walk her dogs, and we returned to the topic.

Fieldnotes, August 2021

We talked some more, focusing now on attachment styles and the impact trauma can have on a person's life. Her face became a little more serious as she told me some information about her family. Previously she had alluded to the abuse her and her sister had suffered as children. Today she told me that her grandmother on her dad's side had been extremely abusive, and that a few years ago she had found out that her grandfather had sexually abused her sister. She told me this in the context of forgiveness – she had found it extremely hard to *forgive her dad for allowing that to happen, but now her dad was dead she has had to make peace with this. She explained it in the sense that she would never forgive her dad for what he let happen to them as kids, but she could manage that pain. She told me some more details about the complex relationship she had with her dad, and how she felt he never grew a spine, despite the fact that he was abusive towards their mother. Her genetic disorder was passed down from her dad's side, and I sensed what I can only describe as tired resentment towards her late father, alongside pity for things which could, or perhaps should, have been. Within all this, there was also huge amounts of love and grief.*

We talked a little bit about how victims of abuse, especially women, often do not get justice. Our conversation turned towards her sister again. We were close to a children's playground and I really did not feel it was appropriate to ask more questions about what had happened to her sister in this context. The dogs were barking like mad every time anyone walked past and drew attention to us. Instead, I asked what Jennifer thought the impact had been on her sister, and she told me that it was a classic trauma response, meaning her sister hid herself away. We talked about her sister's weight, and how this in turn does not aid the chronic pain her sister experiences. But this itself is important, as it demonstrates how trauma is tied up in complex ways with the body – not just in the sense of it being an aetiological cause of pain, but instead the trauma contributing to the production of a body which experiences pain.

All the perspectives discussed above demonstrate that there can be multiple, co-existing, explanations for chronic pain. The commonalities which emerge surround ideas about what trauma 'shocks' or 'triggers' to do to the body. The physicality, or embodied experience, of the trauma experienced by these participants are all identified as contributing to, rather than causing, pain. Trauma is seen by participants as forming part of their past, but also being ongoing in the present day. When describing their lives, traumatic experiences are seen again and again: domestic abuse, poverty, chronic illness, early death. These experiences are representative of the types of structural violence which often constitute life in certain areas of North East England.

This chapter considers the ongoing suffering experienced by the women who took part in my research. This suffering was seen to have a 'knock-on' impact on how their bodies produced, and processed, pain. Rather than 'causing' pain, adverse experiences throughout these women's lives contributed to the chronic pain states they lived under. Through this understanding of causality, ideas about the trauma-pain connection and the somatisation of pain become complicated. As I have demonstrated above, chronic pain preceded experiences of violence for many of my participants. For others, violence was not seen as existing at a fixed point in the past, but rather served to increase the sensitivity of the body to experiencing pain in the everyday.

3.4 Conclusion

This chapter has contributed to ongoing conversations around chronic pain, trauma, and violence. Often, violent experiences can be represented as something that 'happened' to participants in their past. In biomedical and popular discourses, violent experiences are thought to predispose a person to developing a chronic pain condition, or even to trigger the pain itself. Consequently, causal links are drawn between violence and chronic pain, with violence existing in the past and pain in the present.

It became clear to me that the connections that are often made between violence, trauma, and chronic pain are much more complex than a simple unidirectional link. This chapter aims to lay the groundwork for the rest of this thesis by viewing the experiences of my participants through the lens of structural violence, so as to represent the way participants understood their own pain. By using interview data and fieldnotes, I have shown that ideas about the link between violence and pain were very complex. Often the women who I worked with had multiple aetiologies to describe their chronic pain, some centred around violent things that had happened to them, but others very much grounded in the biological functioning of their bodies. These ideas of biological malfunction, sensitivity, and damage will be discussed at length in the chapters that follow.

This chapter serves as a starting point for a key theme that runs throughout the rest of this thesis; how structurally violent conditions can lead to ongoing chronic pain states in the present day. Rather than a simple formula (violence + trauma in the past = chronic pain in the present), traumatic and violent experiences extend from childhood, into the present, and were occasionally predictive of things that might happen in the future. When Thelma told me that she thought her disability had made her more vulnerable to domestic abuse, this vulnerability had a predictive quality and quickly tips the formula mentioned earlier in this paragraph on its head. In Thelma's eyes, chronic pain increased her vulnerability to the abuse she experienced at the hands of her ex-husband.

The remainder of this thesis aims to further explore the structural vulnerabilities experienced by women who live under the diagnosis of chronic pain in the present. As this thesis progresses, I look to the future to contemplate how this structural violence is resisted in various forms, and how the concept of 'hope' is ever-present (if sometimes faint) for those living under the diagnosis of chronic pain. However, before all of this, I analyse another important part of my participants' pasts; the process of 'being diagnosed'. In the next chapter, I analyse how a person comes to be diagnosed with chronic pain. In sum, this chapter is not about the trauma and violence experienced by my participants, but rather is about how ideas around violence in the past can overshadow and influence understandings of the origin of chronic pain.

4 Chapter Four: Diagnosis Histories

‘Being diagnosed’ is an event; something which happens to a specific person, at a specific point in time. The diagnosis, often simultaneously shocking and long-awaited, has implications that extend from the past, into the present and towards the future. For the women who took part in my fieldwork, receiving a diagnosis to ‘explain’ the symptoms that they had been experiencing for years was a key life event. In this sense, a diagnosis is something that marks a specific point in ‘the past’ much more than any of the experiences of violence discussed in the previous chapter. A diagnosis is something a person simultaneously ‘has’, ‘is’, and ‘lives under’; it is both a process and a category (Blaxter 1978). After the point of diagnosis, how a person moves through the everyday is altered – many different futures emerge on the horizon after a diagnosis is placed upon a person.

The experiences that led up to the point of diagnosis were often told to me as a story grounded deeply in the past. As I sat with participants, they ‘looked back’ and told me about ‘what happened to them’ before, during, and after their diagnosis. This story was often the very first story told to me, prior to any discussion of what living with chronic pain was like, or how it impacted their lives. This chapter will discuss how these stories were told, and why this is important. Throughout, I consider why the point of diagnosis is such an important temporal marker in people’s lives. I consider diagnosis as something that occurs in a person’s history. In what follows, I focus mostly on the stories of the women who took part in my research who had received a formal diagnosis of chronic pain at some point in their medical history. However, within this, I also consider those who have deduced their own diagnosis(es) long before a formal diagnosis, via their own research or interactions with other chronically ill people.

4.1 Second zoom call with Ivy: 13.1.21

The webcam image of my face flickered and disappeared, and was replaced as Ivy appeared on the screen, bounded by the ‘Zoom’ window which I had opened on my laptop. It was early January 2021 and the second time we had ‘met’ virtually. Ivy is an ex-nurse who lives in rural County Durham. She has a diagnosis of fibromyalgia and uses buprenorphine patches, alongside pregabalin, to manage her pain. She was brought up in the centre of Newcastle but had moved out to the countryside in adulthood, and had been settled there ever since. I was sitting in my home office and after appearing on my screen, I could see that Ivy had settled into an armchair which was (I assumed) in her living room. We chatted for a little while, to break some of the awkwardness of being on Zoom, but I soon decided to embrace the strangeness of the situation and get straight to my interview questions. I asked her, very broadly, to describe to me how her pain ‘started’.

In her soft Newcastle accent, she told me that the origins of her illness came from experiences she had had with her reproductive system for many years. Her pain started in childhood, especially after she’d started her period. ‘I used to pass out, things like that’, she told me. ‘When I was 18, they thought it was me kidneys and they did loads of tests, pyelograms etc, and then they realised it was endometriosis… I was 19…20ish’. I expressed shock that she’d got a diagnosis of endometriosis (a painful but understudied condition where tissue similar to that which grows in the uterus grows in different parts of the body) so young and without too much difficulty, and she explained that it was down to a trusted GP who had realised something was wrong and sent her for tests at the hospital. She was told that one of her ovaries was ‘mush’ and that she wouldn’t be able to have *children. After training as a nurse and working for a few years, she explained to me that she had managed to "fall pregnant" twice. Over the next few years, she gave birth to a son and a daughter.*

She recounted the story to me of how her pain had worsened over time, especially after giving birth. I remained silent on my side of the screen, other than to nod in agreement or ask a clarifying question. What follows is Ivy's own account of her experiences across a period of many years:

'Mark was born in '81, in August. And it was the winter of '82 that I started getting these flu-like symptoms… it was like a really bad flu. After that I was never free of pain, but it was never in the same area… but a lot of it I put down to the endometriosis and the tiredness of working and looking after kids and things like that. I had to have a total hysterectomy by the time I was 32. They removed the womb, cervix and both Fallopian tubes, the total left ovary and left a part of the right ovary. I got help with hormones and things like that… but even after that… after that I was still getting a lot of pain in different areas. Like a flu-like symptom, but not the flu. Pain, tiredness, joint pain, aching, sometimes in my fingers, my back, my neck. And then they had to take the ovary away that they'd left, because I ended up with a big cyst on it. So, all of these things… so many different problems, you know? I was, as I say, I worked for a long time after having my son and daughter and went through a traumatic divorce. Again, that took a toll on me… I had flare ups of pains, in no specific area but in different areas. And it was tiredness the whole time and trying to struggle with two younger children and trying to work night duty, and I just put it down to that kind of thing. And then, I was at home one day on a day off, and I went to stand up and the pain in my foot was just HORRENDOUS, I couldn't put my foot down at all. I went to the doctor and they sent me to the hospital. They said it was one of the joints in my feet, like arthritis. So, they tried injections, hydrocortisone injections, to no avail. And that's when they decided to take the bone from my hip and fuse my foot. I was in plaster for quite a while, they took it off and by that time the other foot had gone, because it was taking the weight. So, they decided to do the same thing on the other side, take the bone from the other hip kind of thing. And I fell, and my ankle came out of joint and they hadn't realised, because it was in plaster. It wasn't… it was to support the foot more than anything. So then the tendons got stretched and so the ankle still actually comes out of joint and I have to wear on a brace on it all the time'.

'So were all these surgeries to do with arthritis then?' I asked. 'They kept saying it was arthritis!' Ivy replied. 'They kept saying it was rheumatoid… loads of different tests and things like that. But I was having flu symptoms at the same time and tiredness. The problem is, every time I've had an operation I've haemorrhaged, and I've had to go back into theatre and have a blood transfusion (at this point Ivy chuckled at the look of horror on my face). I've had loads of different tests, platelet levels etc., etc. And everything is normal. The first operation I ever had was when I had my tonsils out when I was 10, and I haemorrhaged then. And I needed a blood transfusion'. I asked Ivy how many times this had happened. 'I've had quite a few operations, especially as I say with having endometriosis. After having a hysterectomy, I haemorrhaged. I was literally out for three days then, because what happened was… I kept telling them when I came round something was sloshing around inside me and they kept saying everything was fine, it was okay, they kept turning me… and then my blood pressure dropped... and they had to take me down to theatre on the hospital bed. If they'd have transferred me to a trolley, I'd have burst open. So, when I had me feet done… one of them, I bled from the hip where they took the bone from, and the other time it was the foot I bled from. And also after the hysterectomy I had thickening of the tissue, quite a few times I'd had operations on the same area and there's nerve damage there anyway. But I

started reading up on it myself, and I thought I had fibromyalgia, but no one would acknowledge fibromyalgia anywhere'. I asked roughly when this was, asking… 'so was this in the 80s?', as I was uncertain of time. 'This was in the 90s. My brain, my nurse brain… I was getting concerned about all the different areas I was having the pain. My neck for example, they put me on amitriptyline for that. But every time I seemed to have a trauma in my life, like needing an operation – because after this I needed my gallbladder taking out – every time I've had an operation the pains in my body seem to have got worse. I would go through stages where… I have IBS, tiredness, fatigue, generally sometimes I don't want to get out of bed because I'm aching all over. I don't know why! You know?.

I asked Ivy if she knew where the symptoms were from. 'Sometimes I just wake up in the morning and I'm dragging myself around and I can't pull myself together, for no reason' she replied. I asked her if she thought she 'has' arthritis or 'had' arthritis? 'Yes I do!' She responded. 'They said I had arthritis. And I've had blood tests which say it's rheumatoid, but they say it's not showing signs properly yet, but to me it is. The blood tests show its rheumatoid, but yeah. My hips hurt but that is more osteo[arthritis]. My hands are horrendous, but also I've got Dupuytren's, that's thickening of the tissue across the tendons in the hand. About 4 years ago they operated to try and cut some of the thickening away, but actually they made it… it was on my left hand luckily. But they made it worse'.

Ivy held her finger up to the webcam for me to look at. Her little finger was curled towards the palm of her hand. 'That's it - can you see the scar?' She asked me. I nodded and said that I could, moving my face closer to my laptop so I could take a closer look. There was a small white line across the base of her hand. 'This finger is down constantly now, it hurts, catches. My hands get so cold I have to sit in the house with gloves or a hot water bottle. But that's both hands. My knuckles are starting to feel like arthritis. So, it's a mixture of both I think. It wasn't until I saw the rheumatologist a couple of years ago, at Durham. He was on secondment from the Freeman Hospital. It was only then that I was actually diagnosed with fibromyalgia. He started touching certain pressure points which hurt'. I asked Ivy to expand, interested in how this long story stemming from her childhood was cumulating in a fibromyalgia diagnosis. 'So you went to a doctor for an arthritis appointment?' I asked. Ivy replied: 'yes it was a rheumatologist I'd been going to at Durham. We hadn't had a consultant for quite a while, but as I said it was a gentleman from the Freeman who'd come over. He started pressing certain points on my elbows, shoulders, round my knees. They were tender, but for no reason. Straight away this doctor said to me 'you do know you've got fibromyalgia?'. It was the tenderness of those points that gave it away.'

I expressed surprise about how quickly the diagnosis had occurred after so many years of build-up, and asked if Ivy had thought she'd had it from way back in the 90s. 'Yes, from different things that were happening to me, for example the IBS, because people with fibromyalgia seem to get IBS for some reason. At times I can't speak properly. My words don't come out and I get the brain fog. I can be in the middle of a sentence and, it's quite embarrassing. I take groups as I say, and I'll…' (Ivy faltered and laughed). 'See there my mind's going, I'm chair of governors at a school, and I could get up and talk and know what I wanted to say, and it wouldn't come out. I get really bad migraines, which get worse. One of them, they thought I'd had a stroke because of my speech, it was slurring, but it was just to do with migraine. And it was all these little things, where I was like, I've started writing them down and reading the symptoms of fibromyalgia and I seemed to tick boxes all over. But it's not the same all the time'. I asked Ivy if she'd broached potentially having fibromyalgia with other *doctors, in general practice or otherwise. 'I'd broached it with my GP' she replied, 'but all I got was that they didn't really know about it… it was just all in the mind and things like that.'*

Ivy's story is emblematic of the diagnosis histories I was often told during my fieldwork. For many participants, messy constellations of symptoms (often occurring since childhood) crystallised into a formal diagnosis, often of fibromyalgia, after years of presenting to health services with many complex problems. Many of these problems entailed their own diagnostic histories – Ivy lists the things she *has*: endometriosis, arthritis, Dupuytren's. However, these diagnoses (although often painful themselves) appear secondary, or supplementary, to the story of Ivy's pain and how she obtained a diagnosis of fibromyalgia to explain everything else. These stories also show the kind of liminal 'boundary work' that diagnosis and classificatory systems do, which will be discussed in the next chapter of this thesis. Ivy considered the most important boundary she crossed to be obtaining the diagnosis of fibromyalgia, as it helped her to bundle up all the other symptoms she had experienced, which were not fully explained by her other diagnoses.

This chapter, however, focuses on how many of my participants considered diagnosis as something that *happened* to them. It considers how diagnosis itself is interwoven into people's pasts, while echoing into the present and forward to the future. In this chapter, I first discuss how diagnosis has been studied and written about within the social sciences and humanities, including anthropological work in this area. The close interweaving of participants' histories of diagnosis and their histories of illness has led me to use Hacking (1995)'s 'looping effects of human kinds' as a driving theorical focus of the chapter.

In reflecting on the ethnographic data in this chapter, I use Blaxter (1978)'s understanding of diagnosis as both 'process' and 'category' to describe the ways diagnosis is present in the pasts of my participants. I consider how Hacking's ideas of how classificatory systems 'loop and loop' can be applied to the diagnoses that my participants lived under. I focus first on the diagnosis histories that were told to me to explain diagnosis-as-process. I explain how different chronic pain conditions are 'created' in the pasts of my participants, and how this results in living 'under diagnosis' (Martin, 2007) both in the present and in many multiple possible futures. I then consider diagnosis-as-category, in order to describe what happens *after* people are placed under a specific diagnostic category. Using an ethnographic example from a support group, I explore how people can 'loop' into new diagnostic categories through biosocial interactions with others. I consider the importance of Hacking's (1995) 'self-ascriptive kinds' to how diagnoses are navigated and negotiated in the everyday.

This chapter considers the stories of how people obtained their diagnoses, and subsequently explores how they begin to live under diagnosis. I discuss why what diagnosis a person has, and how they get it, is important. It lays the groundwork for the remainder of this thesis, which considers the different facets of life as a chronically ill person. In this chapter, I aim to demonstrate how living under diagnosis has historic, mundane, and predictive consequences.

4.2 Diagnosis in the social sciences

In the social sciences and humanities, understandings of diagnosis can be viewed more broadly as sitting within literature surrounding theories of medicalisation dating back to the 1970s (Zola, 1972; Illich, 1976), alongside Parsons' influential work on the 'sick role' within social systems (Parsons, 1951). Importantly for this chapter, sociologists have viewed diagnosis as both a static category, and a dynamic process that is undertaken by the physician and placed upon the patient (Blaxter, 1978). As social scientists became more interested in how and why an individual becomes classified as sick, questions around how diagnoses occur have become increasingly important. These questions explore not only the different socio-medical practices that can cumulate in a diagnosis (Mol, 2002) but also relate to 'autopathography', or how a person tells the story of their own life through the lens of disease (Hawkins, 1999).

Anthropologists have historically taken an interest in diagnosis as process: how diagnoses happen, and what they mean to people. This interest is famously articulated under the lens of the 'illness narrative' as a classic research focus in medical anthropology (Kleinman, 1988). The concept of the 'illness narrative' can be used interchangeably with the concept of 'pathography' more often used within sociology and history (Hawkins, 1999) . It is fundamentally focused on how a person understands the story of their illness in context, and how they relay this experience to others. This focus on experience is what is of key interest to this chapter.

Importantly, medical anthropologists working in this area have also explored how illness is categorised in different cultural settings, and under different healthcare systems. For example, within medical anthropology, the concept of 'culture bound syndromes' (also known as folk illnesses) attracted considerable attention in the 1970s and 1980s (Kleinman, 1980; Simons and Hughes, 1985). This research has led the emergence of more critical perspectives on diagnosis. This can predominantly be seen through discourses around different mental health diagnoses in different cultural settings, and debates around the validity of different classification systems such as the Diagnostic and Statistical Manual of Mental Health Disorders (DSM) (for examples see:Nichter, 1981; Kirmayer, 1986, 2006; Good, 2012).

These critical perspectives on diagnosis are influenced heavily by Foucauldian approaches, and are concerned with the mechanisms of power that govern engagements with healthcare, and categorise different bodies in different ways (Foucault, 1973). These categories will be addressed later in this thesis, where I will consider the forms of biocitizenship (Petryna, 2002; Rose and Novas, 2005) that emerge alongside different diagnoses when individuals seek state support for their illnesses. However, while these more critical perspectives on diagnosis are important to how I understand people's entanglements with their diagnoses, they will not be the focus of this chapter. Instead, I take the diagnostic categories which shape chronic pain as being very important in themselves, and consider the practical aspects of how diagnosis is woven into the life histories of my participants. I use this as a starting part to explore the different aspects of life living under a diagnosis of chronic pain.

Over the last 20 years, anthropologists working on diagnosis and diagnostic categories have used perspectives from sociology (Jutel and Nettleton, 2011) and the history of science (Rosenberg, 2002) to consider more how diagnosis impacts people's lives, rather than critiquing the process and act of diagnosis itself. Lochlann Jain (2007) discusses how prognosis (a natural consequence of diagnosis for many oncology patients) makes cancer *material* for those affected by it, whilst holding within it the potential for multiple pasts and futures to emerge. A prognosis has a predictive quality. By necessity, chronic illnesses do not come with a specific prognosis – instead, they endure and do not have an identifiable end point. However, a lack of prognosis and a declaration of chronicity holds, in itself, a temporal orientation.

Volumes such as Manderson and Smith-Morris' (2010) *Chronic Conditions, Fluid States: Chronicity and the Anthropology of Illness* have focused on how the category of 'chronic illness' interacts with different diagnostic categories. They note how the temporal markers (acute, chronic) used to denote different types of illness are inherently flawed. For Manderson and Smith-Morris, the temporality in the language used by biomedicine is not neutral. They draw from Foucault to argue that when physicians invoke time, through the diagnosis of a given disorder, it is representative of specific 'historical and cultural' (read: Western) traditions that view disease as linear and easily describable through bounded categories (Manderson and Smith-Morris, 2010: 13).

Here, we can see how discussions of time have contributed to critical diagnosis studies. Discussions of how time is created through diagnostic categories can provide an interesting framework to understand the everyday experience of illness. Ivy, whose story was presented in the opening of this chapter, had only (on paper) had a diagnosis of fibromyalgia for the past few years. In reality, she had been experiencing the symptoms and effects of the disease for decades previously, but had had her symptoms dismissed as psychosomatic or relating to something else entirely. Ivy's fibromyalgia story is not a linear one, but one which best represents the enduring nature of chronic illness – technically Ivy had only lived under the diagnosis of fibromyalgia for a short amount of time, but in reality fibromyalgia had overshadowed her life for many years prior to diagnosis.

More recently, anthropologists have produced work which pulls together many of the threads of research discussed above, focusing on the critical analysis of global diagnostic structures, and producing research which focuses on the far-reaching impact the act of diagnosis can have on a person's life (Smith-Morris, 2015). Other research has focused more on the everyday experiences associated with being diagnosed. Manderson (2020:2) emphasises that life is often 'mapped out' after diagnosis. The periods before and after diagnosis both impact how a person experiences (or, lives under) diagnosis. This 'mapping out' is key to this thesis and articulates well how people become 'placed' in time at the point of diagnosis.

Following this line of thought, this chapter considers how diagnosis changes a person's understanding of their own illness narrative, pathography, or history. These understandings can change how they experience their illness as they move through everyday life. As is the case with Ivy's account of her own fibromyalgia diagnosis, when looking back at what has happened to her she was able to distinguish the oddities in her experiences and explain how the diagnosis of fibromyalgia was 'created' at a specific point in time. This was despite indicators in her clinical history suggesting to her that she perhaps 'had' fibromyalgia long before the diagnosis given by a rheumatologist. Ivy always reflected on the strange things which had been happening to her body through the lens of her current fibromyalgia diagnosis, despite her pain being put down (at the time) to her other painful diagnoses such as endometriosis or arthritis. The classification into a diagnosis of what, before the fact, may have been a tangle of unidentifiable pains represents a pivotal life moment. This moment is fixed in time and becomes incredibly important to the lives of people under the diagnosis of chronic pain. For my participants, diagnosis is part of their past, but the difficulties which come alongside the diagnosis of a chronic condition continue to haunt the present, stretching into the future.

For the women who took part in my fieldwork, the history of their diagnosis was (for the most part) synonymous with their history of illness. Living under diagnosis is a life shaped by some form of order, regardless of whether or not the diagnosis resulted in improved symptoms, or access to more effective care.

Here, I want to return to Hacking (1995)'s 'looping effects'. Chronic pain conditions like fibromyalgia are, according to Hacking, a human kind. As described by Ivy, many of the people diagnosed with chronic pain conditions like fibromyalgia are diagnosed by a process of exclusion. There are no specific standard medical tests, biomarkers or scans used to diagnose fibromyalgia. The diagnosis is often given when other diagnoses, such as rheumatoid arthritis, have been ruled out or do not explain the extent of the pain. Through the act of diagnosis, my participants became subject to the looping effects that exist within the diagnostic categories used to describe chronic pain. In this sense, their inclusion into the human kind of chronic pain allowed their pain to 'become' more real at a specific point in time. In the remainder of this chapter, I discuss how chronic pain becomes included in these looping effects. This occurs both through the looping effects which surround the process of gaining a diagnosis, and through the maintenance of those looping effects as people become part of different diagnostic categories.

4.3 The making of chronic pain: Diagnosis-as-process

The process of gaining a diagnosis of a specific chronic pain disorder, and the moral dimensions surrounding diagnosis, raises a key issue – whether people are believed about their pain. There is a large amount of philosophical literature that discusses the 'epistemic injustice' (Fricker, 2009) experienced by people who live with chronic illnesses (Carel and Kidd, 2014; Ho, 2011; Buchman, Ho and Goldberg, 2017). People with chronic pain, and other invisible illnesses, often experience disbelief during encounters with medical professionals or other official bodies. This disbelief precedes diagnosis but can also occur afterwards. As will be discussed as this thesis progresses, encounters with medical professionals become especially problematic when they involve the prescription of opioid painkillers or other medications with the potential for addiction or 'abuse', or relate to the allocation of different state benefits.

Many of my participants experienced systematic disbelief when they visited the doctor complaining of pain, and had significant periods of time when they were interacting with medical professionals but lived without a diagnosis. Ivy's story, which opened this chapter, demonstrates how many years can pass between the onset of symptoms and receiving a diagnosis. In this sense, diagnosis is a process of which the apex is the absorption of a person into a specific classificatory system (Blaxter, 1978; Hacking, 1995).

In this section, I want to highlight the disbelief, or uncertainty, that often leads up to the point of diagnosis. Through diagnosis a certain amount of legitimacy is obtained, which can have ramifications for how a person lives under diagnosis. I demonstrate this further by providing, in their own words, the diagnosis histories of two participants, Jennifer and Ella. Jennifer lives with a rare, painful genetic condition which was diagnosed later in life. By contrast, Ella has a diagnosis of fibromyalgia alongside another diagnosis of ME (Myalgic Encephalomyelitis – another contested illness). By presenting these two narratives, and showing that these two women had both experienced clusters of curious symptoms prior to diagnosis, I hope to demonstrate that it is *at the point of diagnosis* and inclusion into a certain diagnostic category that an individual becomes absorbed by a certain human kind. However, not all human kinds hold with them the same moral values. When human kinds are demonstrable through abnormalities in genetics, scans, or bloods, they become closer to a natural kind. Diagnoses which do not have this evidence are more at risk of the 'epistemic injustice' (Fricker, 2009) which those with chronic illnesses are so often subject to.

4.3.1 Jennifer's diagnosis history

'For me… I've known that I've had differences since I was a little kid. The genetic condition was passed down from me dad, but I believe he got it spontaneously. Obviously, it happens to people all over the world but it starts somewhere in your family and no one knows why. Part of the condition is that your spine is slightly curved, our bottoms stick out a bit more. I never thought nowt more of, I never thought anything more of it, but as I've got older I've realised that this natural stance adds more to my pain. As far as going back, remembering, I had bother with the way I used to walk. I saw a specialist somewhere. I was just young and I don't remember what it was, but I got sent for physio. They used to push my foot and stretch the tendon on the ankle to make me walk flat on it. I vividly remember these exercises were painful, forcing something to stretch. But that's physio.

It wasn't really obvious until I remember being in high school. It was a very slippery day outside. Me friend Joanna, she was built like a tank, and we used to walk to school together every day. Best buddies we were, and she jumped on me back for a piggy back. We were carrying on being stupid and then me knee popped out, and it was ***out****. I didn't know whether to carry on, going to school. I ended up hobbling home and my grandma, who was looking after us. She put me in this little car, forced me to bend me knee— she had a little yellow mini at the time— and took us to the doctors. I was in floods of tears, it was agonising. She was so embarrassed, she stormed in ahead of me, not helping us out the car, nothing. The doctor fiddled about with me knee and said I'd done something with me tendons, nothing more. But, since then, I've had bother with me kneecaps, they pop out. Anyway, that was my main thing when I was younger, issues with me knees.*

It wasn't until I fell pregnant with me first son. You know you go for your antenatal appointments and you go for your urine tests and so on, there was loads of protein in my wee. Subsequently I ended up under a unit in Oxford, they were pioneering at the time, they ended up looking after me in case I had pre-eclampsia. Cos protein in the wee is a sign of high blood pressure. So, I went on to have him, perfectly healthy little boy except I knew straight away he had the same thing as me, except I didn't know what it was at the time. He's fine, a strapping laddy now. And then I fell pregnant again shortly after having him, and unfortunately I lost that baby. And then I fell pregnant again and had a successful pregnancy, but again with monitoring as I was spilling protein the whole time, because the thing I have is related to the way my kidneys are formed. So, had him by caesarean, cos he was awkward. He's a wonderful boy, but he does suffer with his own pains, he complains about his elbows. His pain seems to be starting at 15, but at least we know what it is and what we can and can't do.

It was after we moved back up here, I was under the care of the renal people again, because of the blood and protein. It was a guy at the Freeman hospital in Newcastle, he was probably the third consultant I had seen. You know, people were trying to work out what was going on. I think people have a wellness bias, don't they? They thought I looked alright. I had to have a kidney biopsy done, that did hurt mind! They initially diagnosed— I can't say it all!— gloma-fro-fro-froitis or something, something to do with the filters in the kidneys. But this guy came in and said 'I know what's wrong with you! Can I have a look at your knees?' And he was looking at me hands and proper examined everything. And he said, 'I think you've got Johnson's syndrome[8] *—- we'll send you*

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[8] Johnson's syndrome (name changed to protect Jennifer's identity) is an extremely rare, and painful, genetic disorder.

for genetic testing'. I went to the Centre For Life for this, took both boys and they swabbed them at the same time and that's when we were diagnosed with Johnson's!'

4.3.2 Ella's diagnosis history

'The first issue that I noticed. I went to a school where I had to wear a skirt and tights all the time, I always noticed getting the tights over my thighs. It was painful. On cold days they'd turn purple and red, and I'd think 'does this happen to everybody?'. At this point I was 13 or 14— just… at high school, I remember it hurting a lot when I was at a desk. We'd be hunched over a desk, writing, and I remember that it hurt afterwards. I just, at 14 years old, thought it was normal. I just thought I was tired. I was falling asleep in some classes, one in particular. In English when we used to read stories. We'd be reading and I'd just fall asleep. I remember, I was quite active, when I was 14, we moved and I went to school and we lived in Newcastle… but then we moved to Northumberland and I'd have to get a train into the city and walk into school. I put a lot of the tiredness down to 'this' or 'that' and made excuses for everything. When I look back, they were the first signs.

When I was 16, my mum and dad had an accidental baby. I didn't have any siblings until that point, and I noticed putting his car seat in and out of the car would be really painful to me. A really intense pain, like if you've lifted far too much. And it wasn't really that heavy. Even the position to get car seat in the car, it hurt. I started complaining of a really bad back. My mam and dad didn't believe us, they thought I was attention seeking because my brother had been born and I was feeling left out. But that wasn't the case at all. I went to the doctors and they went to … they recommended physio because they thought I'd pulled something. So, this doctor, she wasn't very nice, sort of said 'you've pulled something, we'll get you with the physio'. So, I listened and went to the physio, and it made me worse. It was horrendous, I would start collapsing because it felt like my spine couldn't take my weight anymore. It didn't happen often, but I'd be standing, and my back would spasm. Even getting ready on my dresser, I'd be doing eye makeup and leaning over, and my back would sort of lock into place, and go into spasm. It was like an intense electrical feeling all the way down my spine, and I couldn't move. This was at 16/17. It was really painful. When you're that age, you think 'what is wrong with us? What's going on? This is getting worse? Am I gonna be in a wheelchair?'. So, I went back to the doctors, and I said that the physio is making me worse. Her answer was that there was nothing else they could do, and I was left without any help. She told me to take paracetamol and ibuprofen when it was really bad, but it was never enough to move the pain.

At this point my memory gets a bit funny, I think I just left it. Or, went back again. It wouldn't have been that long because I know what happened when I was 18. I went to the doctors, and I said, 'you know, I'm in a lot of pain and it's getting worse'. Their answer was 'painkillers'. Me being naive I got put onto… I think I was 16 actually… they referred us to the arthritis clinic, and at the same time they were starting to put us on painkillers as soon as I turned 18. I had been at the arthritis clinic from 16, they did MRI scans on my back, and they thought I had scoliosis. We were really worried about that, a friend of mine had a double curvature of her spine and had to have metal rods put in her back. My dad paid for a private appointment to go to the doctor, to see if it was correct or not. It turned out it wasn't… correct. Sorry, this bit's all a bit disjointed because I can't remember what happened at what time. But I was still in high school at this point, before I'd turned 18, I think. I was 16 or younger, going to the arthritis clinics, first they were seeing if there was anything wrong with my *spine they could operate on. They found abnormal wear and tear at the bottom so sent us to the arthritis clinic, the doctor I was seeing was a surgeon. He said there was a bit of fluid and wear and tear on the spine, but there was nothing to operate on. They could see something wasn't quite right but couldn't see what it actually was.*

I went to the Freeman hospital to see the doctor there, and she … diagnosed me with ankylosing spondylitis – another word for it is bamboo spine. As it goes on, you end up with a lot less movement in the spine. What I found really frustrating – maybe I'm just naive but I always said to them 'you can't see my spine fusing together yet, so how can you diagnose something without evidence?'. My analogy is always 'you can't call a thief a thief, without proving it'. So how can they diagnose something without evidence to back it up? This used to really frustrate us because they wouldn't listen to what I was saying. Whenever they asked if I wanted copies of what was sent to your GP, and whenever I'd get the copies in the post, I'd get upset. I felt like they were tailoring my story to fit what they wanted it to fit, I didn't think I had … I didn't think it was impossible that I had it, but I wanted to make sure if they thought I had something to make sure it was true. At this point, they were giving me anti-inflammatory drugs, and when they didn't work they'd put us onto a different one. Whenever I stopped one I'd put the rest of the pack into a box, and this box became full quite quickly. I'd just think 'what are these drugs doing to me?'. Some of them were really big and hard to swallow. I just kept thinking 'if you're giving me these drugs and it turns out I don't have arthritis, are they going to damage me long term?'. They even did hydrocortisone injections and told me I was only allowed so many of those. They didn't make a difference, nothing was helping, and they weren't listening. At this point I was going with my mam because I was still under 18, and I'd have to write down the questions because what would happen was every time I went to the hospital I'd start crying out of pure frustration. It got to the point where I couldn't speak, so I'd write these questions down and give them to my mam. And she'd get annoyed with me for it and I felt like I had no support. I felt like people thought I was making it up. It was really frustrating. It might have been different if I'd have been older, at 17/18 you aren't a great communicator, and people treat you with kiddy gloves. I was so fed up with it.

Eventually, my question to the consultant, one of them anyways was … 'if I come back in 2 years' time and my spine hasn't started to fuse together, will you still say I have arthritis?'. They wouldn't answer the question and I was getting more and more frustrated. A few years later I had another scan and my spine hadn't started fusing together and they said 'so we're thinking you don't have ankylosing spondylitis, so we'll be discharging you'. It made me feel shit, there's no direction. What do I do now? I'm still in pain and I know something's not right. So that happened. Just before that I'd been sent to a different physio, and I was very weird about it. When I went to see this woman, I told her I had very little trust in physios, and she identified that I have hypermobile joints and said, 'have you looked into hypermobility syndrome?'. So, I did some reading and mentioned it to the doctors. Some of them said quite possibly, some of them said I didn't have enough of the hypermobile joints. So, I was really confused. I had 2 diagnoses with no evidence to back either up and I was just left thinking 'ok'. At this point I was probably only just 18, fed up, went to go and see the GP, and the GP was the one who started us on painkillers. It wasn't a consultant. We started on codeine, said they weren't shifting the pain, and they were like 'we'll try the next ones up' and then we went to tramadol. All in a very short space of time. Sometimes I'd go back and say the tramadol wasn't working, and then they offered me morphine! I worked on the weekend, and I *was driving around taking 8 tramadol a day. I was on a different planet. I don't really remember what happened with all the different doctors and stuff.*

I was working so many hours, trying to make some money. When I was about 20 I was doing 18 hour shifts. When you do that much, all bar work, cleaning, waiting tables, when you're doing that much obviously your pain levels increase and you have to take more to keep going. It went on like that for years, taking more tramadol. I felt backed up against a wall when I was taking 8 a day and still in pain. All the while I was being investigated at hospital. At 20, I moved from Newcastle to Leeds for university. At this point I decided I wasn't going to let whatever was going on with me interfere with me having a good time at uni. I totally ignored what was wrong with me for a full year, but I wasn't working, so life was easier. I'd saved up enough not to work during that first year. I sort of ignored what was going on. Second year of uni, I had to start working again and started taking painkillers again. I still… got my prescriptions from my home GP and was using them intermittently. The second year, it's all a blur, the second year it got worse. It was back with a vengeance, and I had to start working again and increasing the painkillers. I didn't have loads of contact with GPs in Leeds, but in third year I started struggling with depression. I wasn't sleeping, I'd go for days not sleeping which made the pain worse. I was muddling through.

In my third and fourth years, I met my partner who I'm with now and we moved in together and I had to change GP. They could see I was on tramadol and they started trying to give me other tablets, steroids. I put a lot of weight on them. They never found a steroid that worked for me, and putting on weight made the pain worse. But they were adamant they wanted us off the tramadol, and they did really want to help us looking back, but I wasn't at the point where I could do that. During that third year I was on a placement, and I noticed the pain and tiredness was getting worse. I was nodding off at the wheel driving to and from placement. It was awful, I felt really tired, but I put it down to normal life. I'd think back and think 'my god, when was the last time I felt this tired'. It's like when you've got the flu, sitting on the sofa watching telly in your pyjamas, not moving too much, and then your eyes close. It's like that kind of tiredness. Sleep wasn't recharging my battery – logically you think 'I'm tired so I'll sleep to feel better'. But I didn't feel better! The last time I felt like this was when I was 16 and I actually fell pregnant, and I couldn't keep my eyes open at school. I had an abortion, and after that I felt better. But the tiredness I was having felt like what I experienced while having morning sickness and stuff, it was exactly the same as that.

It took 7 years from starting to go to the doctor to get diagnosed, I was 21, so and it was… it must have been the same year my bladder went wrong. It felt like I had water infection all the time, painful to wee. And it kept happening. I got sent to the Nuffield in Leeds, and they said my bladder had shrunk to the size of a walnut, and now I'm on tablets for that for life. For some reason, that's been getting worse recently too. So, that happened at 21. Sorry it's all so mixed up. My bladder is scarred because my apparently…. The nerve signals that come from it tell my brain that I have a full bladder before its full. They think this is all to do with fibromyalgia. In Leeds I was put on anti-epileptics to try and sort the nerve signals. I'd been to the pain clinic, they'd suggested a TENS machine.

And then, I went to see a rheumatologist and he was really good but couldn't do a lot. I kept going with uni, seeing the same doctors, adamant they wanted me off painkillers. What I found during my last year of uni was *that I'd be working and feeling in pain. Say I went for a cigarette break, just for a rest and to sit down. But once I got back up, I'd get a horrendous pain in my feet and back. Sometimes I'd get home and have to ring my partner to come and help us out of the car. It felt like someone had took a hammer to every single bone in me foot. I'd crawl up the stairs because it was so painful.*

I came back home after uni. I needed to be where my support network was. I went back to work for my dad part time, and I'd find that I turned up an hour before, or an hour later than I was meant to. I'd get so confused about time, and I was getting depressed again. I'd come back from work, fall asleep. Was back to taking tramadol, felt like a zombie. Where did I go after that? I went to my GP and told them about me tiredness and stuff like that. I'd always suspected that I had ME. When I was about 18, I asked about it at the hospital, and he said 'you don't want to be diagnosed with ME, it's just a group of symptoms'. And I said 'I understand that, but if I have it, I have it? Right?'. He told me I didn't have ME, and once again I asked what would happen if I came back in 2 years with the same symptoms, and he wouldn't answer the question. I knew then that I had ME, but that was the beginning of it. And then, after talking to my GP years later I went to go and see a doctor at the hospital who decided that I had a sleep problem, and started giving me melatonin… and that was good. At the same time, my mam and dad split up after 25 years together, and my dad took a lot of his anger out on me and I stopped working for him. He was very emotionally abusive to us, and we didn't speak for 3 years. I just walked out one day. I was trying to find another job, but it was like everything hit me at once. It was stress. I was not in a good place at all. I found during the week I wouldn't go out of the house, walking was harder. Everything became harder to do. And then, I started to get a little bit better, I was back taking a lot of tramadol. I felt so depressed that sometimes I'd take two at once just so I could feel nothing. I was abusing it. I went to my doctors and told them I had been abusing it due to how depressed I felt. And they were like 'no! We're not taking you off it'. Before this, my original prescription was for 30 tramadol, that's what I had from being 18. I said I knew the drug was difficult to come off, but I wanted help to come off it. I left with a prescription, still running now, for 100 tramadol per prescription!

I honestly think I was born with a gene that has an on-off switch. I think… its all the same thing that caused mine, caused the fibromyalgia, caused the ME. I think I got a virus that flicked the switch. I got chicken pox when I was young and – when I look back I can't tell you exactly when I started experiencing pain because I thought it was normal for so long. I wouldn't have questioned it if I hadn't have experienced other things. So, I think I got chicken pox, and that flicked the switch. And I was working from being 12, so I didn't rest. And then when I was 14, I got shingles. And then I got something called Pitriayasis Rosa, a rash that goes like a Christmas tree. I spoke to my cousin who's a junior doctor, and I've spoke about it with him for years and he finds it interesting. All these things I've had relate to the herpes virus. I think the herpes virus flipped that switch in my body, and it stays and mutates and mutates. That's what I think. Especially with shingles, mine happened and it was really weird. I think there's something to do with my immune system that doesn't work properly. I think it's got into my nervous system and messed with all of the signals. It would explain my bladder and that stuff. I can't have anybody touch my arms unless they know what's wrong with us, its like having a massive bruise that someone has hit with a hammer.'

What these two very different diagnosis histories can show is that the *type* of human kind people are classified into can have extensive, and important, moral ramifications. In Jennifer's case, as soon as the genetic tests verified that she had Johnson's syndrome, her illness became legitimate. Although she occasionally has trouble accessing painkillers from medical professionals unfamiliar with her diagnosis, her pain is now accepted as having a specific causality and can be traced back to (and blamed on) a genetic origin. Consequently, her diagnosis can be linked to something abnormal in her genetics, and she is for the most part believed when she reports her pain to others. Her illness was made material through the genomic sequencing she and her sons underwent. Prior to the genetic confirmation of her illness, physical clues which changed the shape of her body – strangely shaped thumbs, click-y hips – were used as evidence of some biological abnormality which was the cause of her pain. Through these biological clues, and further genetic testing, Jennifer was absorbed into the human kind of 'Johnson's Syndrome'. Within this human kind, there were clear rules of causality linked back to genetics, and so the process of diagnosis stopped with her genetics.

For Ella, the story is more complex. At no point during the account presented above did she tell me exactly when she was diagnosed, other than to explain her initial incorrect diagnosis of ankylosing spondylitis, and to discuss the controversies around her ME diagnosis. At some point, she mentioned that she had been diagnosed with fibromyalgia, but didn't specify exactly when. Ella's diagnosis story jumps around in time, and by its very nature is confusing and convoluted. It perfectly exemplifies the nature of how diagnosis sometimes occur; often, the linearity which is expected to emerge alongside biomedical categories is simply not there. Throughout her account, Ella details the biological theories she holds about the cause of her disease, in order to further loop and loop into the diagnostic categories of fibromyalgia and ME. On paper, biomedically, she is 'normal'. However, through her illnesses narrative she provides a sophisticated, causal explanation of her illnesses which is oriented around the herpes virus.

What can be noted for both these women is that the process of seeking and obtaining a diagnosis transforms experience into medical knowledge (Smith-Morris, 2015,2020). Obtaining a diagnosis is a partial ticket to being believed, while navigating the uncertain worlds of chronic illness. There are different levels to this belief, which are centred around whether disease is demonstrable using diagnostic techniques and equipment. Prior to Jennifer's diagnosis, her symptoms were ascribed to various possible problems, but after a chance encounter with a doctor who was familiar with her very rare genetic disorder, her chronic pain became neatly packaged within the remit of Johnson's syndrome. In practice, this does not change the pain she lives with in the everyday but allows her to present a reason for why this pain occurs to clinicians she engages with. As a consequence, she is believed when she says she is in pain.

Furthermore, looping effects were created as these women began to understand their respective illnesses not just as things they may have 'had' from being children, but as a category which could be applied to both their experiences in the everyday and potentially to their futures. As Hacking (1995: 368) notes, human kinds 'enable us to re-describe our past to the extent that people can come to experience new pasts'. When a person is diagnosed with chronic pain, their past experiences become clearer. For Jennifer, years of strange symptoms which impacted her entire body could be traced back to a disorder she had from birth. For Ella, her various chronic diagnosis could be packaged up, and she was able to theorise the origin of them herself, through the model she presented to me of the herpes virus 'flicking a switch' in her body.

Furthermore, these diagnostic categories had a predictive quality. For Jennifer, genetic testing had allowed her to predict that her children too would suffer from chronic pain as they aged. She also had some semblance of an idea of what the future *might* look like for her, as the disease progressed. For Ella, this was again less clear cut. However, her diagnosis meant she was able to state the things she was, and was not, able to do in the everyday. For example, she 'couldn't' have people touch her arms without this causing her significant pain.

The predictive quality of chronic pain diagnosis is something which will be discussed at length towards the end of this thesis, but here I want to emphasise that looking back at how a diagnosis was obtained allowed both Jennifer and Ella to begin to make sense of time. By looking back at what happened, the women I spoke to during my fieldwork were able to make sense of things that had been happening to them for years. Through the telling of their diagnosis histories, my participants were able to communicate how their chronic pain had existed years prior to being diagnosed, through the description of what happened to them 'before'. In this sense, diagnosis is a process; something that a person 'becomes'.

4.4 'I don't have fibro, but…': Diagnosis as Category

From a sociological perspective, a diagnosis is a form of social currency, distinguishing between normality and abnormality. It is not only a process, but is a category too (Blaxter, 1978). As illustrated in the two diagnosis histories described above, these diagnostic categories can include some, and leave others floating in a space in-between sickness and health. Furthermore, a diagnosis can impact upon the medication or other healthcare a person can access, and can alter the 'sick role' an individual is able to occupy (Parsons, 1951). Notably, a lot of the literature I draw upon here once again can be traced back to sociology within the latter half of the 20th century. By using this literature to understand chronic pain as both category-and-process, we can more fully understand how a person comes to live under diagnosis.

During the course of my fieldwork, the importance of inclusion (or not) into a given diagnostic category became increasingly apparent. Diagnosis-as-category seemed to be especially important at the meetings of the chronic pain support groups I attended during the latter half of my fieldwork. I now consider the importance of what diagnostic category a person was placed into, and how this categorisation influenced interactions with others. Diagnosis-as-category can again be understood through Hacking's (1995) looping effects. As discussed in the literature review, what I saw at support groups aligns well with a subcategory of Hacking's human kinds; self-ascriptive kinds. These self-ascriptive kinds move power from 'knowers' to 'the known'. In other words, they move some of the diagnostic power from clinicians to those experiencing symptoms. Here, I give an example of when I observed these self-ascriptive kinds operating in a support group setting:

4.4.1 Chronic Pain Care, September 2021

After months of trying, I had managed to get an invite to attend a local chronic pain support group. Most of the groups had begun meeting again after the period of lockdown restrictions in England had lifted, and I had messaged the group admin on Facebook to see if it would be okay if I attended a meeting in person. I had received a reply saying I was in luck, and that the support group would commence meetings again from September. The meeting took place in a village a few miles outside of Durham City. It took me a while to find the place, relying on Google maps to navigate me through tiny backstreets. I finally arrived at where the *meeting was to take place— it looked like a typical community centre in the UK, which hadn't seen much investment for a few years. I was welcomed by Iona, the admin who I had spoken to on Facebook. She told me to make myself at home, and I took a seat. The tables were arranged in a circle, so everyone who attended the group was able to face each other easily. Iona asked if I wanted to explain why I was there, and I handed round my information sheets and specified to the group that I was really interested in how people with chronic pain live day to day, and what the importance of these groups were to their wellbeing.*

While we waited for the last few people to arrive, I began chatting to the couple sat next to me. I found out they were called Mildred and George— Mildred immediately offered up that she had been diagnosed with fibromyalgia, and that George 'didn't have chronic pain' but attended in his capacity as her carer. With them was their friend Maeve. Again, Maeve's diagnosis was the first thing I learned about her. She told me she 'didn't have fibro' but had 'really bad back issues'. More importantly for her, she told me how she had lost her husband to cancer a few weeks ago and began to cry as she specified that she was attending the group to find something to do with herself, and that it had been really helping. I felt surprised by the amount of information being offered to me as a complete stranger, and became aware of the vulnerability which comes alongside attending support groups like these.

By this point, the room had filled up and I explained why I was there again. Iona waited until there was a lull in the conversation and asked the all-important question: 'how is everyone feeling?'. After a moment's silence people began to speak about the pain they had been experiencing. Everyone was met with groans of sympathy and offers of support from the other group members. As I got to know the members of the group across this first session, I learned that not only were descriptions of experiences of pain important to the group members, but that the kind of diagnosis they had formed a huge part of how they identified themselves to me, and to others. I heard repeatedly phrases like 'I don't have fibro but…' which were used to describe how many people had chronic pain that was either awaiting diagnosis or had been diagnosed as something else entirely. Halfway through the session I turned to the lady who had been sat next to me the entire time without saying much, and asked her if she had fibromyalgia too. She introduced herself as Linda, and smiled at me shyly and shook her head, telling me she had arthritis in her spine. She told me she has also had two strokes over the last few years and as a result can't feel a lot down the left side of her body, other than nerve pain. Looking at my information sheet, she also offered up that she took codeine to manage the arthritic pain she experiences.

Throughout the session I tried to talk to as many people as I could, to gauge how keen they were to take part in my research and to try and read whether I would be welcome at the group the following week. Towards the end of the session, I began chatting to a middle-aged woman who I had been introduced to as Gill. I asked what kind of pain she experienced, having realised this was the kind of language used to talk about these things. She told me she has something called sarcodosis. I didn't know what this was and said I'd have to look it up, and she explained to me it was something to do with her spine. She also offered to me the fact she had been diagnosed with both inflammatory arthritis and osteo-arthritis, and 'probable fibro'. As she was describing all this to me from across the table, she explained that her doctor refused to diagnose her with fibromyalgia, but she had all of the symptoms the other people who attended the group who did have fibro had, so from what she understood she had it too. I asked her what she did for pain relief, and she stood up and swivelled around. She showed me a small patch which looked a bit like a plaster stuck to the back of her arm. This, she explained, was a *buprenorphine patch which she had been given from the pain management clinic for her Sarcodosis. For her, it works well as it prevents her being in pain during the night.*

The importance of 'what' a person has became ever-more apparent to me as s visited these in-person support groups. As I have discussed throughout this chapter, people often introduced their pain to me by telling me the story of how they were diagnosed. However, it was only when I watched people interact with each other in a group setting that I realised how important diagnostic categories were to how people talked about their illnesses. What a person had been diagnosed with was key to the interactions that occurred in the group; those with certain diagnoses were able to offer advice and insight to others. Through claims to different diagnoses, group members were able to make specific claims to forms of support and advice from others. This constitutes part of the biocitizenship (Petryna, 2005) which will be discussed in Chapter Eight.

What can be demonstrated through this vignette again follows Martin (2007)'s concept of 'living under diagnosis'. In Martin's ethnography, the diagnostic rules which cluster around bipolar disorder were reinforced, but also challenged, by the sort of conversations that occurred at support groups. For many of the people I spoke to at these groups, diagnostic labels had been applied to them, and from there had created a certain truth about their embodied experience of pain. The point of diagnosis was the point their pain became 'real'. However, these diagnostic labels were not only produced by medical professionals.

Take the example of Gill, who was careful to tell me that she had 'probable' fibromyalgia, despite having an official diagnosis of a few other chronically painful conditions. Gill experienced all of the same symptoms as her peers in the support group who had 'confirmed' fibromyalgia, and through interactions with the group had deduced that she too fit into this diagnostic category. This was in lieu of a formal diagnosis from her GP. By explaining to me that she had 'probable fibro' she was able to align herself with those in the group who had had it confirmed, circumventing the more official diagnostic processes which occur in clinics.

By interacting with her peers in the support group, Gill was able to claim the fibromyalgia diagnosis for herself and access the some of the biosocial support which came alongside having the diagnosis. Alongside claiming the label, Gill was able to include herself within the human kind of 'fibromyalgia' and become part of the looping effects which constitute it. Superficially, it may seem like diagnosis-as-category stems from 'what a person has', which is produced only through interactions with medical professionals. However, by looking to how diagnoses are negotiated in support groups, it is possible to see the looping effects of human kinds in action. People come to live under diagnosis through different routes, and become absorbed into different human kinds in multiple ways.

4.5 Conclusion

This chapter has explored how the women who took part in my research understand their own diagnosis histories. For my participants, obtaining a diagnosis represented a life event which is deeply embedded in both personal and medical histories. This chapter has described the diagnosis histories of three of my participants, in their own words. I have also explored how these diagnoses impact social relations within the different support groups I visited as part of my research.

By viewing diagnosis as both category-and-process, it is possible to view it through the lens of temporality. Discussions of time are of central importance to this thesis, and what I have tried to do in this chapter is demonstrate that notions of time are central to understanding what happens when a diagnosis happens, and what happens after. Through my data, I have focused on how participants oriented their diagnosis, and by extension themselves, in time. Inclusion into the category of 'chronic pain patient' is often contentious. It is obtained through negotiations with healthcare professionals which can span across decades. Sometimes, these negotiations are messy and do not result in a clear-cut diagnosis, causing the person to navigate these categories outside of the clinic, and uncover a diagnosis which fits their symptoms.

In this chapter I have first provided a brief overview of how diagnosis has been understood in the social sciences and humanities more broadly, and by medical anthropologists more specifically. The aim of this chapter is not to contribute to the large body of literature critiquing the very concept of diagnosis itself. Instead, I have explored what diagnoses do to a person's understanding of their own history. Using the stories of three of my research participants; Ivy, Jennifer and Ella, I have shown how looping effects can lead a person to 'live under' diagnosis. I have demonstrated how chronic pain categories are created and co-created, in a looping fashion, through the stories told to me by my participants.

This chapter has also discussed diagnosis-as-category, through an ethnographic account of events at a local chronic pain support group. What a person 'has' or 'doesn't have' is a marker of identity and is used in these groups to both communicate experiences and assert legitimacy in the everyday. My ethnographic examples demonstrate that even after a formal medical diagnosis, diagnostic categories are constantly being affirmed, negotiated, or renegotiated, beyond the bounds of the clinic. To live under diagnosis is to be constantly moving across, and in between, the looping effects described by Hacking (1995). To have (or to be without) a specific diagnosis changes how a person moves through the everyday.

This chapter provides further background to the rest of this thesis, and aims to emphasise that to my participants diagnosis was endlessly important. Without a diagnosis, chronic pain lacked shape. With a diagnosis, chronic pain became real. This remains true even when great difficulties in accessing care persisted after the point of diagnosis. By telling me the story of their diagnosis, I learned about my participants' pasts in great detail. Diagnosis is something that happens to a person – in this chapter I have shown that it is part of an individual's history, and is something which forms a key part of identity. But, as Lochlan Jain (2007) argues, it has tendrils which reach deeply into the present and impact the potential for a certain kind of future. The remainder of this thesis will consider how these diagnostic histories impact in the present – how my participants live, day-by-day, under diagnosis.

SECTION TWO: THE PRESENT, OR LIFE UNDER DIAGNOSIS

5 Chapter Five: Chronic Illness at the Borderlands

> ‘With most things, you either die from it or they can make you better…. With fibromyalgia you’re just in limbo’
> - Support group participant

In Chapter Four, stories of how participants came to live under diagnosis were discussed. This process is not a passive one. It was sought out, and in some cases even fought for, for specific reasons. One reason was to be able to attain the ‘correct’ care. Theoretically, the correct diagnosis is a clinical tool which allows doctors to treat patients in an appropriate and clinically effective way. Clinical guidance states that the ‘gold standard’ for chronic pain management involves a biopsychosocial approach, which incorporates multidisciplinary perspectives to help individuals manage their pain well day-to-day (Mordecai *et al*., 2018). Theoretically, a chronic pain diagnosis should allow a person to access this ‘gold standard’ care.

In reality, living under diagnosis can complicate interactions with healthcare professionals in surprising and complex ways. By exploring how people interact with these health services while living under diagnosis, it is possible to begin to understand how health inequalities can become embedded in health systems. Access to care for chronic pain in the North East is often disjointed. Evidence has demonstrated that even though the area has the highest prevalence of chronic pain in the country, provision of this ‘gold standard’ care is limited in the area (Mordecai *et al*., 2018). This follows the famous maxim favoured by scholars of health inequalities, the ‘inverse care law’. This law states that ‘availability of good medical care tends to vary inversely with the need for it in the population served’ (Tudor Hart, 1971: 412).What is like to live in a place where this law is enacted? How did the women who took part in my research try and access chronic pain care in North East England, after the point of diagnosis?

In this chapter, I consider what it means to interact with biomedical healthcare systems while living under the diagnosis of a chronic pain condition. As discussed in my literature review, chronic pain is problematic for biomedicine (Good *et al.,* 1992). As a result of this, chronic pain occupies an uncomfortable liminal space in biomedicine, becoming a stigmatised state of being (Jackson, 2005). This chapter focuses on the challenges faced by my participants when they sought healthcare after their diagnosis, and how these challenges manifested in very heterogenous ways.

All forms of chronic pain – even those placed under a specific diagnosis – can be seen as occupying a liminal state. To demonstrate this, I draw from the literature in medical anthropology on chronic pain and liminality, alongside the writings of Chicano theorist Gloria Anzaldúa. Anthropologists have understood chronic pain as liminal, and I use this literature to think about how (using Anzaldúa’s conceptualisation) people who have a chronic pain diagnosis live ‘at the borderland’. Even when a diagnosis had been obtained, access to care was fragmented. Care was navigated as my participants moved through the everyday and gained experiential knowledge about how to live under diagnosis. While living under a diagnosis, my participants were constantly dancing across and in-between different boundaries: real and unreal, sick and well, deserving or undeserving.

To exemplify this liminality, I use ethnographic examples focused on two very different aspects of this fragmentation: accessing care for a chronic pain diagnosis, and having care for other health issues denied or delayed *because* of a chronic pain diagnosis. In the first ethnographic section, I explore how my participants navigated obtaining different painkillers. In the second, I consider the concept of ‘diagnostic overshadowing’ (Reiss, Levitan and Szyszko, 1982) to understand what happens when living under a chronic pain diagnosis absorbs within it all other potential health problems.

People who live under a chronic pain diagnosis have to develop an embodied knowledge of how, and when, to seek healthcare in order to have the best chance of getting what they need. It asks several questions: When is it appropriate to ask for opioid painkillers? What is to be done when specialist healthcare provision in your local area is severely limited? How does a person ask for painkillers without being seen as ‘drug seeking’? When should symptoms that do not fit within the bounds of a diagnosis be further investigated? When should this be pushed for, even if doctors have refused further investigation? This chapter concludes that seeking, or negotiating, healthcare while living under diagnosis requires what Anzaldúa describes as *la facultad.* This concept, outlined in the literature review, is essentially concerned with how specialist knowledge about the world is obtained through marginalisation. In this chapter, I demonstrate the working of *la facultad* through describing the how participants developed very nuanced ways to access care for their chronic pain, through a delicate attunement to their own body.

5.1 Liminality, stigma and pain in anthropology

In Chapter Four, I discussed how diagnosis is understood by many of my participants as being a life event occurring in the past. Diagnosis represents the crossing of a boundary – from being undiagnosed, to living under diagnosis. Thinking about these boundaries and their consequences will form much of the theoretical orientation of this chapter.

This focus on boundaries is something medical anthropologists have attended to. Much of this work draws from ‘classic’ work in medical anthropology, such as Douglas (1966)’s *Purity and Danger*. Douglas discusses the logic of beliefs around pollution, and analyses how in different cultural contexts, dirt is not a static concept but rather a symbolic one. It is ‘matter out of place’ (Douglas, 1966:44). Things which cross, or challenge, pre-set boundaries are considered dirt, and generate disorder and discomfort. Much of the research within medical anthropology on chronic pain uses the concept of boundary crossing to explore why people who live in and around these diagnostic categories are seen by biomedicine as being challenging, and even potentially dangerous.

A notable example of this is Jackson, (2000)’s *Camp Pain,* an ethnography based upon fieldwork in the ‘CPC’, a pain clinic founded in 1972, where the author herself had been a patient. Following from the assertion in Good *et al.* (1992) that personal experience is the most important (and effective way) to understand chronic pain, Jackson uses her ethnography to explain how locally constructed meanings of pain were formed in the clinic. She argues that ‘pain is a quintessentially postmodern topic’ (Jackson, 2000:10) as chronic pain was a cultural category which did not exist until the 1970s. Here, again, we can see the importance of understanding the diagnostic categories used to organise chronic pain as being subject to Hacking’s (1995) ‘looping effects’. As these categories ‘loop and loop’, people who live under them are constantly crossing the lines used to demarcate different diagnostic categories, and are further absorbed into them.

In further articles, Jackson (2005) uses the ideas presented in *Camp Pain* to explore the stigmatisation of chronic pain. She concludes that sufferers of chronic pain occupy a place of liminality, existing in a place that struggles to be cohesively defined. Jackson utilises Douglas (1966) to explore how liminal states are threatening, or even abhorrent, to the patient, doctor and medical establishment. They straddle boundaries, becoming 'out of place' as neither physical or psychological patients, attacking accepted binaries within biomedicine. Drawing from classic sociological work on stigma (Goffman, 1956), Jackson argues that because of its liminality, living under a diagnosis of chronic pain is a stigmatised state of existence. It is this stigmatisation which contributes to the barriers which chronic pain patients find in seeking and gaining help.

Jackson's fieldwork in the CPC expanded ways of looking at pain in anthropology. The concept of 'real and unreal' pain was first introduced by Jackson in the chapter 'Pain as Lived Experience' (Good *et al*., 1992), but elaborated upon in Camp Pain (2000) and following work (2005). In the CPC, Jackson observed how performances of pain experience were communicated to herself, other patients, and to clinicians. Patients in the clinic grappled with how pain was (or was not) part of themselves, challenging the idea of 'body as object and self as subject' (Jackson, 2000: 146) and building upon Morris' famous discussion of the 'myth of two pains' (Morris, 1991). Here, we can see how those living under a diagnosis of chronic pain have to learn how to delicately navigate their own experiences and understand their pain both as existing within biomedical categories and within their own lived experience.

This boundary line between 'real' and 'unreal' is extremely important and has been discussed in much of the ethnographic literature surrounding pain experience. More recently, Buchbinder (2011, 2012) undertook ethnographic fieldwork in a paediatric pain clinic. Ideas of 'real' and 'unreal' pain are again discussed in relation to the difficult diagnostic categories that emerge when biomedicine talks about chronic pain in children. She observed that diagnosis was not only used to legitimise the chronic pain experiences of the children treated in the clinic, but was also used to cast patients who had specific diagnoses as smart or virtuous. Through Buchbinder's work, we can see how notions of stigma are entwined with that of diagnosis. It is not that a diagnosis removes stigma, but rather that it streamlines it in very specific ways.

Previously, medical anthropologists have used ethnographic methods to explore how diagnostic categories can shape the boundary lines between real and unreal pain. The liminality that surrounds chronic pain can help to explain some of the stigma chronic pain patients face. With this in mind, this chapter will consider further how these boundary lines impact the everyday experience of seeking care for chronic pain.

5.2 Living under diagnosis as a border dweller

Through anthropology, we can understand that living under a chronic pain diagnosis is to live in a liminal state, despite (and in fact because of) the biomedical preoccupation with categorisation. To understand what occurs when diagnoses 'loop and loop', this chapter uses Anzaldúa's (1987) *Borderlands/La Frontera* to contemplate how this liminality manifests. By considering those living under a diagnosis of chronic pain as 'border dwellers', I explore my participants' lives under diagnosis as being in a 'constant state of transition' (Anzaldúa, 1987: 25) that becomes altered through different interactions with healthcare services. Here, I draw from online interviews and text conversations, alongside face-to-face meetings, to demonstrate the awareness developed by my participants regarding when they could, and when they should, seek healthcare. This became especially important when the prescription of potentially addictive painkillers was concerned, due to the moral dimensions surrounding the prescription of these drugs.

5.2.1 Negotiating prescriptions at the borderlands

In practice, living under a diagnosis of chronic pain was often (but certainly not always) the start of a process that allowed participants to obtain different medicines to help them manage their pain. As discussed earlier in this chapter, provision for 'gold standard' chronic pain care in North East England is limited. This 'gold standard' care involves ongoing input from many different clinicians, and as a result is expensive and difficult to access. In reality, the main form of pain management available to my participants was often in the form of pharmaceuticals. Commonly, these would be prescription-only opioid and gabapentinoid painkillers obtained from the GP, which were prescribed for many years without much supervision from the prescribing clinician.

Growing concerns about the over-prescription of these drugs was the origin of this PhD project, and my initial research questions were focused on looking at the conditions that might lead to the prescription of an opioid or gabapentinoid painkiller. However, mid-way through 2021, a significant change in how chronic pain is treated was enacted in the United Kingdom through the publication of new NICE Guidelines for Chronic Pain (National Institute for Clinical Excellence, 2021). These guidelines state unambiguously that no pain medications are to be routinely prescribed for the management of chronic pain. Instead patients should be encouraged to access psychosocial support, physiotherapy and 'self-management' of their chronic pain states.

The implications of this change in guidelines for clinical practice were beginning to trickle through while I was finishing writing my thesis (Kang et al., 2023). However, the contentious nature of the prescription of opioid pain medications had been an ever-present concern for many of my participants throughout the time I had spent doing fieldwork, regardless of the methods they used to manage their pain. Some participants found that they were encouraged to take opioids by their GPs, but if they presented to A&E with more acute pain, told me about how they were treated *'like a druggie'*. Several participants had met doctors in acute care and had been chastised for specifically asking for the same, or similar, medications they had been prescribed for years. Similarly, many participants felt that being taken off their medications would leave them *'with nothing'*, as the forms of healthcare promoted by NICE were simply not available in their local area. As will be detailed as this thesis progresses, I was privy to several instances of the stockpiling of different medications during the time I spent with participants, and began to learn that there were many unofficial ways of accessing pain relief which easily and knowledgeably circumvented primary care.

This echoes what Emily Martin describes in her ethnography of support groups for people in the US who live under the diagnosis of bipolar disorder (Martin, 2007). When living under a diagnosis, especially a stigmatised one, relationships with healthcare providers become difficult, especially when these relationships involve the prescription of medications. Martin describes the double bind her participants and their doctors found themselves in when interacting with each other. If her participants demonstrated too much knowledge about their mental illness, they became less 'mad' through the articulation of this knowledge to their healthcare provider. Having knowledge about the diagnostic categories that could be used to categorise a person as 'bipolar' made a person fit these categories less well. Martin describes this as 'moving across the arbitrary line between the rational and the irrational' (2007:98), once again emphasising the importance of boundary work when navigating life under diagnosis.

This tension between patient and healthcare practitioner knowledge is something I heard about frequently during my fieldwork, especially with regards to painkillers. In what follows, I demonstrate how my participants moved across, through, and beyond the lines which were drawn through interactions with healthcare systems and providers. When people exist at the borderlands, they have to learn to negotiate healthcare outside of what is described by the guidelines. This can manifest in strange ways: either wanting to access opioid painkillers, being denied them and then having to use different techniques to get access to them, or wanting to access different medications and having opioid painkillers be presented as the only option.

Tesco's Café with Amy, June 2021

It was a sticky summer's day towards the end of June 2021. I was in Darlington interviewing some GPs for a project related to my PhD, and managed to sneak out for an hour down to Tesco's café to meet Amy. Prior to this we had only spoken over Zoom or text and I really wanted to take the chance to meet her in person, so I had suggested we meet up for a quick coffee to catch up. We are the same age and had really got on when we'd spoken virtually, and I hoped this would translate across to an in-person meeting. When I arrived, she was already sitting down waiting for me. We walked up to the counter to order some drinks - I got coffee and Amy ginger and lemon tea. The café was empty, and very calm.

We both sat down with our drinks, facing each other, as we had done over screens many times before. I asked her how she'd been doing, and she blew air out of her mouth to indicate a lot had been happening. Her mum, who was currently undergoing treatment for cancer, had had major surgery last Friday. She was now a full-time carer for her for the foreseeable future, alongside her dad. A few weeks ago, she had told me that she had been dealing with extreme bladder pain. This pain was still there and was getting a lot worse: 'Normally I take a tramadol and go to sleep, but a week ago on Sunday the pain started again, and tramadol didn't shift it…. And then it kept going'. She told me how she had tried hard to deal with it, but had ended up calling her GP, who had prescribed her Buscopan over the phone. We both looked at each other, paused, and burst out laughing at the absurdity of prescribing an OTC medication intended to treat irritable bowel syndrome for intense bladder pain which hadn't been shifted by tramadol. 'I tried it for 24 hours… but it did nothing', she told me.

By the following Monday the pain had got so bad she had ended up going to A&E. At this point, I interrupted and asked if I could record her talking, because I was becoming increasingly interested about what happened when people accessed painkillers through more acute corridors such as A&E. I wanted to make sure I didn't miss any details. As we spoke, the sounds of people doing their shopping were all around us.

She told me that by the Monday, it was the longest she had gone dealing with 'this level of pain'. I asked what it felt like. She paused and said… 'well… I still have it… but I'm on Oramorph now… it was like an intense burning pain but every time I went to the toilet it would stab, like incredible cystitis pain. You can't switch off from it'. She described how hard it was to deal with the pain, and that she realised that the only option she had was to go to A&E and seek some stronger pain relief. 'I actually went to A&E in Middlesborough, because that's where I'm under urology', she explained to me. She had gone to that hospital because she knew from *experience that her records wouldn't be shared across trusts, and that she had anticipated that she had a better chance of getting pain relief if the doctors in A&E could access her records and see that she had a history with this kind of thing. She told me that she had been to Darlington A&E before for a problem relating to her bladder, and had been admitted to a gynae ward as that was the closest department that might have been able to help. She had ended up being in hospital for several days waiting to be seen by a specialist doctor.*

'So, I realised there was no point in doing that again', she said, looking slightly worn down by the description of what she had had to do to get some pain relief. I asked her if she went on her own, and she told me that she'd been dropped off at A&E by her dad, who hadn't been able to come in with her due to Covid restrictions. Her mum had been in the same hospital at the time. She joked about how if she had been admitted, they'd have been bed buddies - she'd have been able to circumvent the restrictions on visitors rule.

Amy described how the A&E visit had actually been really positive for her – she had been triaged and taken straight to a bed as soon as they had realised how much pain she was in. 'They were obviously quite concerned' she told me, 'because the amount of times I've been left in pain in A&E is hard to count'. She described how she had been taken into a private room and they tried her first on IV paracetamol. She looked at me again with the same exasperation as when she described being prescribed Buscopan by her GP. 'I told them, I can tell you now that isn't going to work! But you can try it…give it a go. So I had another hour of waiting to see if that helped and then when it didn't eventually they gave me Oramorph'.

The Oramorph worked, to an extent, and then a doctor came who had really listened to what was going on with her. She had warned the doctor that she was aware that her fibromyalgia diagnosis meant that the pain 'could be nothing'. Amy sipped her tea and confessed 'I don't want them to think I'm stupid - I've had it before when I've had all kinds of pain and it's been nothing. But I really needed pain relief'. The doctor had put their hand on Amy's shoulder and said 'but it doesn't feel like nothing to you, does it?'. We both stopped and commented on what amazing care that was, and that it was a shame it didn't happen more often for her. 'I wept!' She told me. The doctor did a urine dip, bloods and a bladder scan and everything looked fine. Instead of saying 'there's nothing wrong with you' the doctor had said 'I don't think this is an acute problem that I can help you with… I think this is part of an ongoing specialist problem'. Amy told me how much this meant to her, to have her pain acknowledged in this way. The doctor had acknowledged the pain relief she had at home wasn't working, and had sent her home with some Oramorph, which she had been taking regularly since. Amy told me that she had decided since then not to leave 'any gaps' in her taking of pain relief, and had been covering the pain with Oramorph consistently to avoid the bladder pain breaking through again.

The smell of pastry drifted across the cafe. We had finished our drinks, but had decided not to get another. Instead we kept on dissecting what had happened to Amy over the last couple of weeks. She told me that she wouldn't have been sitting with me in the cafe that morning if she hadn't taken the Oramorph prescribed by the A&E doctor. 'I wouldn't have been able to do anything except lie down and cry, actually', she said. To access pain relief that worked, Amy had had to use knowledge amassed over several years of living under diagnosis in order to navigate the healthcare system. Throughout our meeting, Amy looked increasingly drowsy and upset, and I felt so much sympathy for what it must have been like for her, looking after a sick parent while experiencing so much pain yourself. We talked about her mum a bit, and she chuckled bitterly as she told me *that she had just realised that the pain relief she was on now was the same as the pain relief her mum was on 'after being cut open from diaphragm to abdomen… and there's nothing medically wrong with me'.*

This example illustrates the kind of boundaries that are often navigated, challenged and crossed by people who live with chronic pain. Amy's bladder pain straddled the muddy lines between acute and chronic. To access the pain relief she needed, she had to calculate the best possible place to access care. This calculation was based on her past experiences. Amy's story demonstrates the kind of delicate, experiential knowledge – *la facultad* (Anzaldúa, 1987: 60) – required by many of my participants when they attempted to access pain relief.

Due to experience, Amy knew that if she tried to access painkillers in a particular clinical location, she was likely to be met with resistance and come away from her encounter still in pain. She was acutely aware of how her previous experiences, diagnostic history, and positionality as a young (healthy looking) woman seeking healthcare would impact the way she was treated when seeking pain relief. When she got to A&E, she had been treated at first only with IV paracetamol, something which she knew would not work. However, she had learned that she would need to demonstrate to the doctors on shift that night that this was the case. By allowing the doctors to give her IV paracetamol, she was able to demonstrate that she needed stronger pain relief to alleviate her suffering.

Amy's story illustrates the difficulties that can occur when trying to access opioid painkillers. As I got to know her better, I learned that most of the painkilling medications she kept in her house had been obtained from different A&E visits. She had no strong painkillers on repeat prescription from her GP. Instead, Amy had built herself a mini pharmacopeia using the painkillers she had been sent home with after visiting A&E. Although she had a good relationship with a caring GP, the majority of Amy's chronic pain relief did not come from primary care, as would be expected on paper. In reality, she had cobbled together a toolkit for *caring for herself,* and only engaged with health services for pain relief when her pain became acute. Her experiences as a young, chronically ill woman completely altered how she chose to treat her chronic pain and meant that she often had to mobilise what she had learned from experience in order to get what she needed.

Thelma's nabilone prescription

Navigating any kind of prescription while sitting at the borderland creates complex issues. This is true even for the participants I met who actively did not want to use opioid painkillers to treat their chronic pain:

It was another sticky day, this time towards the end of July. I had gone into Newcastle, without my phone, to sit in a cafe and do some reading. I arrived back home at about 4pm. I saw I had received a text from Thelma, asking if I could call her. It sounded quite urgent so I rang her as soon as I could. Thelma lives under the diagnosis of 'Complex Regional Pain Syndrome', a condition described by the NHS as 'poorly understood' which in reality seems to translate to 'untreatable'. To manage this pain, she had been prescribed nabilone (a synthetic cannabinoid) which she finds allows her to function day to day. Her previous pain management consultant had advised that she should be prescribed 3mg nabilone twice daily. Previously, she was on very high strength opioids for years, but found they made her feel a lot worse. She hated taking them, feeling that her prescription opioid use had been part of the reason her abusive ex-husband was able to control her for as long as he had. When she spoke to me about the years she had spent taking strong opioids, she spoke of feeling 'doped up' and 'floaty', unable to really process what was going on around her.

The reason for Thelma's distress was that she had received an email from her new pain management consultant, informing her that there were issues with the nabilone supply chain, and, anyway, that nabilone wasn't supposed to be prescribed for conditions like hers. As a consequence, she was being placed on a 'drugs holiday' and her dose being altered without her consent or agreement.

The letter read as follows:

> Dear Thelma,
> Thank you for your recent request for your prescription of nabilone. Unfortunately, we have been informed by our pharmacy that there are supply issues with nabilone 1mg capsules.
> We have discussed the ongoing shortage of nabilone as part of our MDT discussions, and have agreed on a consistent approach to this which is sustainable long term.
> For purposes of equality, we are treating all our patients the same, and we have used this supply shortage as an opportunity to review ongoing prescriptions of nabilone which is NOT recommended by NICE for Chronic Pain.
> It would be difficult to justify restarting nabilone in some cases where pain scores remain high and there is little evidence of functional improvement. We have agreed a ceiling dose of 1mg twice daily.
> We have recommended most patients reduce their dose by 50% in the first instance to cover the period of shortage. We were initially advised that the supply chain would be restored at the end of June, but from July 2021 patients have had an enforced 'Drug Holiday' until normal supplies resume.
> The shortage involves both the 1mg capsule and the infrequently used 250mcg capsule, so it has not been possible logistically to replace one strength for another because of the quantities required to do so.
> We will aim to issue repeat scripts when we have confirmation that the supply chain has been restored and our pharmacy will contact you to arrange a suitable delivery or collection time. We would be grateful if you could inform us of the best number to contact you on for this?

Thelma was distraught upon receipt of this letter. She explained to me how nabilone allows her to function and look after herself and her girls. Down the phone she explained very succinctly that this was all down to misogyny in medicine and clearly due to the cost of the medications, rather than real issues with supply chains. 'I've had a suspicion this would happen Lucy', she told me. 'I've been hoarding my nabilone and taking less every day, so I have enough to see me through fairly well until September even with my dose being reduced'.

She asked if I could help her access some of the academic research done on CRPS and nabilone through my university library account, to prove to her doctor that she did need it. I agreed to do so and send her through anything of note. We talked, for a while, about what she was going to do. She pondered whether she would just go and 'get some edibles' as cannabis has essentially been decriminalised in County Durham. She knew where she could find some good quality cannabis and, before having her children, had taken it (by ingesting it in coffee) with great success. She said that even the thought of doing this made her feel nervous - she is a disabled mother to two disabled children, and she feared that if she ever admitted to using drugs in a healthcare setting a safeguarding report would be put in. I let her vent to me until she had let out all her frustration, as it was clear she needed to voice all the hurt and anger she was feeling about potentially having a medication that worked so well taken away. As our conversation came to an end, she told me about her feelings of disappointment with the health system and how it treated disabled women. With the utmost sadness in her voice, she told me that when her husband received his verdict for nearly killing her in front of her children, he was fined £180. 'That seems to be all my life is worth', she added.

The next day I had emailed her the links to the research she had asked me to find, and we talked over text about the NICE guidelines. I had realised that there were an entirely different set of NICE guidelines for cannabinoids, so I had sent them across to Thelma. According to these guidelines, there were some grounds for her nabilone prescription to be continued as it was. She was hopeful that by contacting the consultant who had written the email and demonstrating that she understood how to read the NICE guidelines (and indeed, that they could be read multiple ways depending on what you were trying to get out of them), that she would be able to get her prescription reinstated.

This vignette shows how difficult navigating prescriptions can be when living under a contentious and/or poorly understood diagnostic category. There are many layers to Thelma's experience. Her condition is so rare that there have been no large-scale randomised controlled trials, or anything else that would be considered by the NHS to be 'a good standard of evidence' to assess what might work for her diagnosis. In the time we spent together, she was vocally anti-opioid, and spoke to me many times about how unwell they had made her, and how she never wanted to be prescribed them again. Consequently, after meeting a pain management consultant who had listened to her needs, she had been prescribed a non-opiate (but much more expensive) medication to manage her pain. This had been reversed after her consultant had changed, with the new doctor in charge of her care believing that nabilone was not appropriate medicine for Thelma, despite her embodied experience of taking it being very positive, and Thelma having felt marked improvements in her symptoms while on it.

Alongside this all, Thelma is highly cognisant of how she is viewed, especially by medical professionals. She is a visibly disabled, single, working-class mother of two disabled children. We had spoken many times about how this changes the way she is treated by healthcare professionals, and she explained to me that she was certain that had she looked and spoken differently, her nabilone may not have been stopped. This was why she wanted me to help her access the academic literature on CRPS and nabilone, in order to demonstrate certain levels of expertise and education to the consultant.

When faced with the possibility of losing access to a medication that vastly improves her quality of life, Thelma had to factor in the risks which would come with taking a still effective, but less legal route to pain relief – using cannabis. The use of cannabis to manage chronic pain will be discussed at length in Chapter Seven. What is important here is to note that the knowledge of the restrictions placed upon a person by their identity further evidences the kind of inherent knowledge border dwellers possess.

5.2.2 Using 'la facultad' to obtain care

Above I have described the stories of two women who live under the diagnosis of chronic pain, who at first glance have two differently opposing aims: to be prescribed opioid painkillers and to *not* be prescribed opioid painkillers. However, both women use their experiences – *la facultad* – in order to access effective pain relief. In both instances, Amy and Thelma have had to use years of experience navigating the world as chronically ill women to try and obtain the prescriptions that help them to successfully manage their pain. Amy, who for all intents and purposes looks like an 'average', healthy 27-year-old woman, struggled to be prescribed painkillers strong enough to help the pain she often experiences. On the other hand, Thelma, who is visibly disabled and uses an electric wheelchair, often had opioid painkillers offered to her as the only suitable alternative to the innovative cannabinoid drug she had found effective.

Although operating with different aims in mind, both women had to use their experience of *la facultad* and live in a way which was constantly reactive to the experiences of life at the borderland. As Anzaldúa (1987: 39) puts it:

> 'Pain makes us acutely anxious to avoid more of it, so we hone that radar. It's a kind of survival tactic that people, caught between the worlds, unknowingly cultivate'

In this sense, both Amy and Thelma used their previous experiences to anticipate what might (or could) happen if they asked for the medications they had found effective. This 'radar' had been developed over many years and through interactions with many different healthcare professionals. Using these two different examples, I hope to demonstrate here not the importance of the different medications, but rather the complex and contested ways chronically ill women need to prove the expertise they have about their own bodies and what works for them. Even with a diagnosis, both Thelma and Amy still needed to operate at the borderlands of healthcare, using learned border logics in order to obtain the medications they needed.

What I have hoped to demonstrate using these two ethnographic examples is that the liminal nature of living under a chronic pain diagnosis impacted the way prescriptions for pain medications were obtained (or were not obtained) by my participants. Even in an area where there is limited capacity for the pain management strategies recommended by the NHS – and where consequently prescriptions often serve as the *only* pain management strategy available – accessing these prescriptions often requires very complex knowledge of how different systems 'work'. This knowledge is developed over time, and requires an awareness of how many different, intersecting aspects of identity might impact interactions with healthcare systems, and change the painkilling medications a person is able to access.

5.3 Diagnostic overshadowing

It is not just questions of access to medications that were important to my participants when interacting with healthcare professionals. In this section, I discuss the concept of 'diagnostic overshadowing' and how access to healthcare for things unrelated to, or not caused by, chronic pain is also altered by the presence of a chronic pain diagnosis. What I want to emphasise here is that living under a diagnosis of chronic pain does not just impact a person's ability to access care for their given chronic pain condition. Having a diagnosis of chronic pain can also impact a person's ability to access other forms of healthcare.

Diagnostic overshadowing is a concept first described by Reiss, Levitan and Szyszko (1982). It is most often used when describing what happens when physical healthcare is denied to those diagnosed with mental illnesses. In most of the literature, it is described as involving the wrongful ascription of the symptoms of physical illness to the manifestation of an individual's mental illness or learning disability. The concept has been taken up broadly by health research which looks to highlight the striking inequalities in clinical outcomes experienced by people with learning disabilities or SMIs (severe mental illness) like schizophrenia, much of which can be traced back directly to diagnostic overshadowing (Jones, Howard and Thornicroft, 2008; Shefer *et al.*, 2014).

However, I found that different forms of diagnostic overshadowing had occurred frequently to many of the people who took part in my research. During visits to support groups, I was often part of conversations where people discussed the frustration they felt when visiting their GP and having *'everything blamed on fibro'*. At these support groups, these women echoed the same story again and again; they would ring up the doctor and describe their symptoms and be told that it was *'just their fibromyalgia'*. They were told a) that there was nothing the GP could do and b) that these symptoms were ordinary for their diagnosis, and nothing to worry about. Many of my participants had experienced worry about all their health concerns being packaged under their fibromyalgia diagnosis, with fear that something might be *'missed'*.

One participant who I met at a support group, Lola, told me a story of falling over at the pub and hitting her head. Upon presenting in A&E, she described how the doctors immediately stopped panicking over her possible concussion and instead directly linked the pain she had visited the hospital with to the fibromyalgia diagnosis listed on her clinical record. A few weeks later, at the same support group, Mia, a newish member, announced that she had finally been given a diagnosis of 'fibro' from her doctor. Becky, the group organiser, looked at her with sympathy and responded '*well…it's all downhill from here. Every pain you have will now be put down to fibro!*'. It was interesting to observe how these experiences were recounted repeatedly in spaces where people met to discuss their pain. Having a diagnosis of fibromyalgia not only facilitated entry into the group but was also used to warn others of some of the problems they may face when interacting with doctors while living under the diagnosis. Using Anzaldúa's words, these warnings seem to form part of how people developed *la facultad,* helping to facilitate the entry of those newly diagnosed into the successful navigation of the borderlands.

Similarly, many other participants I met at support groups described experiencing severe chest pain, often found to be something called costochondritis (an inflammation of the cartilage that connects the ribs to the sternum). This came up when I observed people discussing the types of symptoms they had been experiencing with each other. Often, the pain from this costochondritis was so severe it would trigger participants to visit A&E or call their GP with the worry that they were having a heart attack. Upon investigation, the chest pain was almost always traced back to 'your fibro' and as such many of my participants now no longer worried when experiencing chest pain of such severity. At these support groups, participants often reassured each other that the kind of chest pain described above was '*nothing to worry about*!' and was just an inherent part of living with fibromyalgia and other chronic pain conditions. This concerned me, as from my outsider perspective I felt like any suspicion of a heart attack ought to be taken very seriously indeed. These forms of reassurance demonstrate how diagnostic overshadowing does not just occur in clinical settings, but can be replicated through group and individual experience.

5.3.1 Clare's story

Diagnostic overshadowing therefore has very real consequences for how many of my research participants interacted with healthcare providers. One of my participants, Clare, not only has a diagnosis of fibromyalgia but also a diagnosis of borderline personality disorder (BPD), which is classified under the umbrella of Severe Mental Illness (SMI). What I will present in the following vignette is a collection of experiences that happened to Clare over the course of the year or so she was helping me with my research. I was told about these experiences as they happened, via texts and also in person. The things that happened to Clare occurred gradually but cumulated in her having major surgery in December 2021. Throughout this account, I will highlight the experiences of diagnostic overshadowing she experienced. This diagnostic overshadowing was not always obvious but emerged over time, and with hindsight. Here, I want to emphasise how Clare's diagnoses (as a woman with a contested chronic illness and diagnosis of a 'severe mental illness') have impacted upon the kind of care she received, and how this links back to the literature discussed earlier in this chapter.

10.3.21: Zoom call with Clare

It was a couple of months into the 2021 Coronavirus lockdown in England. I was on a Zoom call with Clare. When she answered the call and her video turned on, I could see that she'd shaved her head. I complimented her on her new haircut and she told me that her hair had become very painful, so she'd decided to save herself some trouble and just shave it off. During the call, we spoke about her mental health issues and how they had been worsening during lockdown, and soon got onto the topic of visiting A&E. She told me about how she ends up going to A&E quite often, always feeling self-conscious and like she won't be believed by the doctors she encounters there. 'I feel guilty every time', she told me, 'and I don't even like morphine'. This was one of the first discussions we had about seeking emergency care, and it became immediately apparent that for Clare, A&E visits were fraught with trepidation.

27.4.21 WhatsApp from Clare

Covid-19 restrictions had partially lifted in England. Clare and I had decided to try and get out for a walk and finally meet face to face. However, the weather had been so bad that we had decided it was actually probably best to stick to Zoom. On the morning we were due to call, I had woken up to check my phone and seen that I'd received a text in the early hours:

> 'Hi. Please don't panic. I'm in A&E. Pain off the scale. So a bit srogged [sic.] up. Won't make the vid call. Sorry. Will text you when I get home or am on a ward.'

Worried about her wellbeing, I replied asking her to let me know how she was when she could, and sent over a picture of my cat in the hope it would cheer her up. Later in the day she messaged me to say she was back home, and that she had had a relatively okay experience at A&E, and for once had been given good pain relief promptly.

14.5.21 Walk with Clare

I met Clare for the first time in person, finally, in mid-May. We met in central Durham, and I wore a bright yellow jacket to ensure she'd be able to recognise me. We spotted each other easily, although her collie, Benny, sniffed me suspiciously. We set off to get a coffee, sitting down on a bench near the cathedral to rest. Clare apologised to me for being so out of breath, and told me about the current pains she was experiencing. We talked and walked slowly around Durham, settling on a route that took us down by the river. At this time of year, Durham always smells of wild garlic in the paths that run along the Wear. As we were walking and admiring the greenery, I asked Clare if anything had come from the A&E trip which had prevented us talking a couple of weeks before. 'Not really' she said, 'but I have been booked in for an ultrasound to try and find out what was going on'. She told me that it was still very tender around where the pain started, describing it as a 'stitch type pain'. We had spoken before about the issues she had had with endometriosis, and we both pondered whether it could all be connected. I thanked her for telling me all this, and more broadly for telling *me candidly when she was in pain and where. At this she laughed, and said 'I've been in pain since I met you, Lucy! But if I want a social life, I have to suck it up'.*

8.7.21 Dog Cafe with Clare

It was an unreasonably hot day for County Durham, and I was due to meet Clare in a dog-friendly cafe she had recommended we try. We ordered iced coffees, and the ice cubes in the glasses immediately began to melt. We hadn't managed to meet up bar texting a few times since the walk we had gone on in Durham, as Clare's health had been bad. We caught up on the last couple of months and sipped our drinks. Benny chewed on a sausage in the corner. Clare told me the tests she had had done after the A&E visit had all come back normal, but the GP she had spoken to was concerned about her liver, and told her to eat more healthily to make her feel better.

18.8.21 Dog Cafe with Clare

I drove over to Clare's after a PhD supervision and we popped to the dog cafe, without Benny this time, to top up on coffee. As we sat down with our drinks, her phone rang. She dashed out to take the call, wincing as she stood up from the table. When she came back she apologised and said that it had been her GP. Recently, she had been experiencing lots of bloating and stomach pain, but thought this was an IBS flare up. When walking Benny earlier that day, she had felt unwell so had rung her GP just check nothing was wrong. She described the pain to me – 'well it's like being pregnant… well you wouldn't know because you've never been pregnant, but that's the best way I can describe it'. Her GP had asked her to come in for 4pm to be checked over, so we had about 20 minutes to drink our coffees and catch up. At about 3.45pm, we left the cafe. As we walked to our cars, Clare described the pain to me in more detail, describing it as period pain going across her stomach with a sharp pain in her belly. She gestured to the places it hurt. When I arrived back home, I saw that she had messaged me to say that she had been examined and needed a blood test and stool sample taking, and that she had been given an antispasmodic (a stronger version of Buscopan) to help with the cramps.

31.8.21 WhatsApp to Clare

At lunchtime, I texted Clare via WhatsApp to see if she fancied a coffee on the upcoming Thursday morning, as I'd be in Durham. She replied, texting me from her hospital bed, saying that she had spent the previous night in hospital with gynaecological pain, and didn't think she'd be out in time to meet me. I texted back asking how everything was, and if she'd like to catch up when she felt better.

11.11.21 Dog Cafe with Clare

After a few months of Clare being too unwell to meet up with me, we finally managed to meet up at the dog cafe again. She informed me that she was scheduled to have quite major surgery the following month. This surgery traced back to the A&E visits she had had earlier in the year. The tests she had had at her GP, and the following hospital admission, had led her doctors discover a 'mass' pressing on her cervix. To have this mass removed, she needed to go to Middlesborough (a 1 hour drive) for the surgery, as it was the only hospital nearby big enough to have the facilities to perform the operation. Due to the way the mass had grown, the surgery was going to require a multidisciplinary team of surgeons – 'I'm having my cervix removed, so that's gynaecology, but there also needs to be input from a bladder specialist and a colorectal specialist'. She explained that the mass was the cause of the pain she'd been feeling, and that it had been pressing on her other *organs. I could see how miserable she felt about all of this, and the despair she felt that multiple visits to doctors presenting with that pain had been so slow to result in any treatment.*

This drawn-out series of events demonstrates the material ways that living under diagnosis can impact how a person accesses healthcare. Clare's medical history meant that her pain and clinical symptoms were always overshadowed by both her fibromyalgia diagnosis and her diagnosis of BPD. Throughout the long period leading up to her surgery, Clare knew something was wrong with her body, something beyond the normal symptoms she experienced. She just wasn't sure what it all meant. Previous experiences seeking acute care had made Clare wary of presenting to A&E. When she had visited A&E (and even when the experience she had there was good) there had been a long delay in finding the cause of the pain she had been feeling. By the time the root cause of the pain was found, Clare required major surgery which had a long recovery period.

Clare's example demonstrates that living under a diagnosis of chronic pain leads people to become stigmatised not only when seeking care for their chronic pain conditions, but also when seeking healthcare for other things. The 'mass' on Clare's bladder which required surgery was causing her pain, but it was not caused by either her fibromyalgia diagnosis, nor her diagnosis of borderline personality disorder. However, when seeking care for this pain, the opposite logic was applied. From speaking to Clare across the period this was occurring, she knew, implicitly, through her embodied knowledge of living with chronic pain, that the pain she was feeling wasn't the 'same pain' as she felt when she was having a fibromyalgia flare up. This, again, exemplifies *la facultad*. It illustrates how deep knowledge of oneself is something that can be obtained when being forced to live at the borderlands.

Clare's story illustrates how the liminal nature of chronic pain required many of my participants to pay close attention to their bodies, sorting and categorising what falls 'under' diagnosis, and what kind of pain exists 'outside' diagnosis. This comes alongside the need to learn how to delicately navigate healthcare systems, meaning that knowledge of what it is like to exist in a chronically painful body is central to how a person engages with the health system around them.

5.4 Conclusion

In this chapter, I have discussed what happens when people who live under a diagnosis of chronic pain seek healthcare. To do this, I have demonstrated how and why a chronic pain diagnosis is a liminal one, and furthermore how those living under a diagnosis of chronic pain are 'border dwellers', existing in a state somewhere between sickness and wellness. Even with a firm diagnosis aligning to a specific chronic pain condition, my participants had problems accessing pain relief, or accessing healthcare for conditions unrelated to their original chronic pain diagnosis.

Using Anzaldúan thought, I have described how my participants navigated the often quite fraught subjectivities that exist around their diagnosis. This chapter focuses on how the women who took part in my research were required to develop very sensitive knowledge – *la facultad* – about themselves and their pain. I have described how this knowledge was then communicated in a way that was a) believable and b) measurable to health professionals. This worked both ways, when accessing painkillers for chronic pain and when accessing care for something else other than chronic pain.

I have used two ethnographic examples to demonstrate the different ways that knowledge about obtaining different prescriptions for pain had been gained over the years. By using Amy and Thelma's stories as contrasting examples, I have shown that living under diagnosis, in these strange liminal spaces, gave these women a strongly embodied knowledge of how they were likely to be perceived when they sought healthcare. This impacts not only how Amy and Thelma interacted with the clinicians they encountered, but also the kind of healthcare they were able to access more broadly.

To complicate matters, a double bind emerges when those living under a chronic pain diagnosis present to health services with other health problems. Time and time again, I heard stories of my participants going to see their doctor for a multitude of ailments, to be told that everything that was impacting them could be absorbed by the overarching category of their chronic pain diagnosis. This phenomena is well documented through the concept of diagnostic overshadowing, but manifests in a specific way when it comes to chronic pain. Using Clare's story, I have shown how multiple forms of marginalisation, including a diagnosis of chronic pain, can overshadow access to healthcare for other health needs.

It is through these experiences, as a collective, that it is possible to see why living under a diagnosis of chronic pain is to live in a liminal state. This understanding of life with chronic pain has been well documented by medical anthropologists when looking at specialist clinical encounters (Jackson, 2005; Buchbinder, 2012). Broadly speaking, what I observed during my fieldwork is that this liminality extends out into many aspects of everyday life. When living under a diagnosis of chronic pain, a person is never living under a fixed category. Instead, they are living at a moving boundary (one which loops and loops), which can be moved and shaped according to the needs and desires of both the individual and the health service.

To summarise, this chapter of aims to illustrate the messiness felt by my participants when they tried to obtain and access healthcare, and the sensitivities my participants had to develop to do so. There are many factors that are important here, but the primary message of this chapter is as follows: living under a chronic pain diagnosis is to live in a liminal state, and consequently accessing healthcare becomes fraught with moral and ethical subjectivities. These subjectivities surround both access to medicines, and access to care for issues outside of the diagnostic category a person lives under. To navigate these subjectivities, I observed that my participants developed and utilised what Anzaldúa termed *la facultad* – through experience they learned, in a very nuanced way, how to attempt to access and obtain the healthcare they wanted and needed.

6 Chapter Six: Gender, Sex, Motherhood and Pain

6.1 27.10.21: Pumpkin carving with Thelma and the girls

I drove up to Thelma's house to carve some pumpkins. Georgina and Bethany were coming towards the end of their half term break. It was near to Halloween and apparently the girls had been bouncing off the walls all day in anticipation of my visit. I was welcomed into chaos. The house had been turned into a children's play centre, the excitement palpable. When I walked into the house, Princess, Thelma's puppy, jumped at me and nearly knocked me over. Thelma was, for once, not wearing makeup. I noted this because I wasn't either; we had discussed at great length our love for brightly coloured lipstick, so it seemed an important observation that both of us had given it a miss on that specific day.

Thelma welcomed me into the living room and I was greeted by the girls, who were in full holiday mode. There was stuff everywhere - socks, sandwich crusts, pens, bags of sweets. Thelma looked exhausted. There were 4 pumpkins waiting on the floor for us. Thelma said she had had loads of issues sourcing them, but had eventually found four large enough at her local Morrisons, and had managed to grab them.

Figure 6: Our pumpkin creations.

We spread a waterproof tablecloth across the floor to try and capture as much of the pumpkin debris as possible, and set to work. The girls drew their designs on their pumpkins and Thelma started to cut them out. I could see how much it was hurting her, sitting on the floor and having to saw through the hard outer skin of the pumpkin with a child-friendly knife. I cut my own design out and we began to slowly scrape the inside of the pumpkins out, the scent of fresh pumpkin filling the room. We fed the dog some pumpkin seeds (supposedly very nutritious for puppies) and Thelma and I chatted a bit while the girls screamed and giggled around us, excited *to see what their pumpkins would look like when they were finished. I had already known that she struggled during the holidays but today really highlighted to me how hard it was for Thelma to manage her own pain, and her children's needs. She is always, always caring for her girls. A huge part of her identity is being a 'good mam' and advocating for her children. She always treats them with patience and love, and tries to teach them how to navigate the world in ways that 'let them be their authentic selves'. We spoke a bit about how hard she has to fight to get her children basic support, and I felt an overwhelming sense of sadness that there wasn't more support for her, too. I helped her clean up the pumpkin mess while thinking about how much more difficult it would have been to do it alone; bending, sweeping and trying to keep an eye on two very excited children.*

Georgina, the youngest, took a liking to me that afternoon. She sat next to me for the rest of the day, chatting to me, telling me jokes, pulling my hair and poking my face. Georgina is tiny, tactile and inquisitive. Thelma has told me numerous times that while Georgina has some understanding of how her mam's pain works, she can't quite understand how gentle she needs to be to avoid hurting her.

The girls sat, eating tomatoes from the packet, as I talked to Thelma about her upcoming appointment at a large hospital in Newcastle. We were both hopeful that the issues she was having with her nabilone prescription would be resolved, as she was seeing the consultant who initially prescribed her the drug in the first place. She told me, defiantly, that she was willing to go to court over this in order to maintain access to this medication. I could see just how exhausted she was by everything, and really felt for her. I could sense this half term break had been especially challenging for her, after the last year and half of Covid-19 restrictions had limited access to life outside the home.

As the girls skipped around us, we talked a little about our families and discovered that our dads were both born in the same year - 1962 - despite Thelma being 10 years older than me. We pondered this, and discussed how this might well indicate some of the class disparity that exists between us, me being born to middle-class teacher parents in their 30s, and Thelma to young working-class parents. Thelma's mum still works, and her dad is in bad health himself, so they aren't always available to help her with childcare.

Later that afternoon, Georgina tipped the contents of a Dib Dab (a sherbert-y sweet) over me, her and the sofa. We were messing around. I was tickling Georgina and in an act of revenge she dumped the packet of sugar over my head. I felt bad that I had got Georgina so overexcited, and I alerted Thelma to what had happened. She hopped over to the kitchen, using her crutch as support and wincing as she went. She came back with a damp cloth and wiped the mess up. Suddenly, she looked at me and said knowingly, 'you know Lucy… dads with chronic pain don't have to deal with this. This is a mam's job, and it doesn't stop just because you're in pain'.

This chapter is about gender, sex, motherhood and pain – a tricky and disparate space to navigate. Motherhood, gender and sex are often conflated, both in popular culture and academic writing. In reality, these terms have multiple different meanings which vary dependent on context. A key epistemic position of this chapter is that biology does not determine gender, and vice versa. In other words, the physical nature of bodies impacts, but does not determine, how gender is performed (Butler, 1990). This has important consequences when thinking about how those who exist within (and around) the category 'woman' experience pain. However, this strange and difficult space brings with it opportunities to discuss the embodied aspects of how both gender and sex impact life under diagnosis.

This chapter discusses three key points; how notions of gender-as-biology impact the experience of chronic pain, how the experience of motherhood impacts pain, and finally what it is like to live under diagnosis in a gendered body. In the first section, I consider how my participants understood their pain as being something uniquely tied to their biological status as women. Often, pain was articulated and made real through a graphic description of reproductive malfunction. In the second section, I explore how notions of 'good motherhood' influence the expectations of reproductive labour (Federici, 1975) placed upon my participants. Furthermore, I demonstrate that motherhood was very much understood by my participants using models of biology. In the final section, I explore how living under diagnosis in a gendered body results in the naturalisation of chronic pain states. For my participants, pain was a natural consequence of 'being a woman', even if this pain emerged from gendered domestic pressures.

The three key threads which form this chapter are intrinsically linked, and consequently are difficult to place into neat categories. However, a key take-home message from this chapter is that biology, sex and gender intertwine and are made material in inter-related ways. What is important to this chapter is to take seriously my participants' understandings of biology, in order to understand more about the embodied experience of living under a diagnosis of chronic pain. As outlined in my literature review, hormones, pheromones and even the genetic basis of sex are all socially constructed much in the same way gender is. Using these ideas, I consider how I can 'think with' biology to question some of the most deeply entrenched ideas around sexual difference and gender, when considering the lives of women living under the diagnosis of chronic pain in North East England. I use Wilson (2015)'s *Gut Feminism* to think through some of the questions that emerge when entering this challenging space.

These ideas link to several key themes that run throughout this thesis. Many of the women who agreed to take part in my research had been subject to gendered intimate partner violence earlier in their life, and if they had children had raised them alone or with limited help. Here, the interplay between sex and gender becomes crucially important to how pain is managed in the everyday. Throughout this chapter, I want to avoid making simplistic and essentialising assertions, for example that biological sex categories are immutable and static, or that gender is solely the social construction of sex. Biology is fluid in the same way gender is. In this chapter, I explore how both gender and sex are co-constructed, and how this impacts the way pain is experienced.

For example, Ivy, whose life history is discussed at length in Chapter Four, spoke to me about her experiences with her abusive ex-husband. She had suffered for many years with endometriosis, and as a result had had a hysterectomy to try and relieve some of the pain it caused her. She told me about her ex-husband's response to the removal of her reproductive organs, telling me that '*he wouldn't go near me… he told me I wasn't a woman anymore*'. Throughout my fieldwork, it became clear that often ideas about biology and notions of how gender and pain interlink can collide in curious, and often violent ways.

6.2 Biology, gender and chronic pain

There are well documented links between 'womanhood' and chronic pain. Multiple epidemiological sources document the links that exist between being a woman and the risk of being diagnosed with, for example, fibromyalgia (Creed, 2020). This research is aligned with the biological and psychological links that knit together experiences of trauma and pain, discussed in Chapter Three. It places emphasis on the complex interplays that exist between pain, violence, gender and sex. For the purposes of this chapter, I want to draw attention to the current biomedical consensus; there are correlations between womanhood and being diagnosed with chronic pain.

When thinking about how sex, gender and pain has been represented in the social sciences, it is pertinent to once again look to sociology. Many qualitative studies within the sociology of chronic pain since 2000 have been focused on the experience of women (for examples see: Råheim and Håland, 2006; Skuladottir and Halldorsdottir, 2008; Broom *et al.*, 2015; Kirby *et al.*, 2015). The specific topics of the papers vary, examining particular diagnostic categories such as chronic pelvic pain or fibromyalgia, through to larger structural issues such as doctor-patient relations. A small amount of literature also focuses specifically on the experience of men (Ahlsen, Mengshoel and Solbrække, 2012) and the experience of older adults (Baker and Wang, 2006). This dominant gendered focus is undoubtedly emblematic of the disproportionate prevalence of chronic pain in women, but seems to lack intersectionality and nuance. The impact of race and class on the chronic pain experience is missing from the earlier literature and only seems to be explicitly acknowledged in more recent years (Buchman, Ho and Goldberg, 2017). Arguably then, work in sociology regarding women's experiences of pain has looked at how ideas of gender directly influence the manifestation of chronic pain.

These gendered aspects of the pain experience were present in what I documented during fieldwork, spanning from how my participants interacted with healthcare providers, to how they took medications. However, I soon realised that something beyond a monolithic and unidirectional understanding of 'gender' was at play. Very early on in my fieldwork it became clear that how reproductive organs and processes contributed to pain was very important to my participants, and constituted a huge part of how they understood their pain. My participants' identities as *females,* and how this identity was influenced by their *bodily functions*, were key to understanding how they navigated life under diagnosis.

Often, the act of giving birth to their children – frequently considered to be one of the most painful experiences a human being can experience – was highlighted by my participants as something which was actually *not very painful at all.* One participant, Andrea, described her birth story to me over Zoom. She had given birth in her late teens, and as it was her first child and she didn't seem to be in much pain the midwives supervising her birth hadn't believed her when she told them that her son's head had emerged from her body. It was only with great persistence that she convinced the midwives to have a look, and even then none of them had believed she could be so far along while showing such little pain.

A 'biological' pain often described to me was pain associated with the condition endometriosis. This issue, which is articulated in medical literature through models of failures in hormonal signalling and abnormal growth of uterine cells, has implications which leaked out beyond the bounds of my participants' bodies. This diagnosis was often a comorbid diagnosis given to my participants alongside 'fibro'. Much like fibromyalgia, endometriosis is a contested illness that often takes many years to be diagnosed. The diagnosis histories told to me often involved a parallel story detailing a diagnosis of endometriosis. The experience of living with endometriosis is well documented in the literature outlined above. However, this literature does not fully address how the category of 'woman' came to be tied up in the diagnosis of endometriosis, and how these categories link to biological processes. When we begin to consider that not all women have reproductive organs (such as Ivy, mentioned earlier in this chapter), and that not all people with female reproductive organs are women, the stories we tell about pain and biology become more complicated.

In the following vignette, I explore how pains originating from female reproductive organs are understood *alongside* how participants performed their gender. Often, reproductive pains were key to how my participants conceptualised themselves and their chronic pain. Menstrual pain and pain relating to reproductive organs was something 'real' that they could locate in their bodies. There was also a general acceptance that painful experiences were an intrinsic part of being a woman; alongside living under a diagnosis of chronic pain, participants also lived in pain under 'womanhood'. In contrast to the strange and unsettling symptoms that often accompanied their fibromyalgia diagnoses, endometriosis and menstrual symptoms provided, in a sense, a comfort that their pain was real and was located somewhere in their hormones, genetics or cells.

6.2.1 18.3.21: Phone call with Julie

I called Julie while she was at Leeds station, waiting for her train back to Newcastle after a night shift. Julie works as a carer and does overnight stays with the woman she cares for, despite living under the diagnosis of fibromyalgia and other chronic pain conditions herself. Julie had contacted me over Facebook after I had posted my research information on one of the local chronic pain groups on there. She was really keen to take part in my research, but her work schedule meant that us actually meeting in person was going to be difficult. As a result, our contact had mainly been over text and via phone calls, while she was travelling to and from work. After the call connected and we had said hello, I asked how she was and she described herself as 'pooped'. She told me that everything in her body was aching. I could hear the sounds of the station in the background, the departing trains being announced by a disembodied voice.

Recently, Julie had been experiencing quite a bad fibromyalgia flare up, so I asked her how that was going. She told me it was bad and described the numbness and pins and needles she has been dealing with, alongside progressively worse pain. She added that a year ago she had a full hysterectomy, and told me that, strangely, she was getting vaginal bleeding still. She was worried about it, and feared it might have been contributing to a lot of the pain.

The conversation moved around a lot. She suddenly started telling me about the arthritis she has in her hips and the fibromyalgia in her hands and feet. She told me that her hands and feet had been swelling up from fibromyalgia and told me she would send me a picture to show me how bad it was, which I looked at on my phone as we kept on chatting. I was familiar with the kind of 'jumping around' that came alongside trying to describe chronic pain – sometimes symptoms are so jumbled up, there's no way to describe them in a way that makes sense to another person.

She told me that she had a week off work, and I asked if she'd be able to rest up, to help her get better from the flare up. She laughed and said that resting makes no difference to her pain either way, so she may as well just keep working and earning money while feeling rubbish. She then told me that while she was off, she had an appointment next week at the hospital to look into the bleeding she had been getting. I asked her if that was due to her endometriosis diagnosis, if it was under a gynaecologist, and she confirmed that it was. She then told me in detail about the bloody discharge she has been experiencing – I was quite shocked she'd tell me something so *personal on only the second time speaking. I also wondered how the fibromyalgia and endometriosis diagnoses interacted with each other, and impacted how she understood her pain. Whenever she spoke about her 'endo', she also spoke about her 'fibro'.*

I asked Julie if she could identify when this particular flare up started. She replied saying she had no idea, sometimes she just sits at home and 'seizes up' and then, that's it. When it gets like this she has to get help from her children doing things like hoovering. We talked a little bit about her children and how they help her, and I could hear the worry in her voice at the prospect of them leaving home in the next few years.

We then chatted a bit, quite aimlessly, about Covid and how difficult things are at the moment. I directed the conversation back to her health and we talked about what she does to manage flare ups. She said normally she would use her TENS machine, hot and cold compresses and painkillers. I asked if she takes any extra painkillers when the pain is bad and she told me she doesn't, and the ones she has prescribed currently don't even dent her pain at the moment. I had asked her what she took before, but she wasn't quite sure on the names of the pills she had been prescribed. Today this was the same, all she could confirm was that a lot of them were the same ones as the lady she cares for takes.

Towards the end of the conversation she confessed to me, in a matter-of-fact tone, that she was heading to A&E when she got back to Newcastle. I felt shocked, as we had been talking about pain for about an hour at this point, and she hadn't mentioned that she was intending to go and get the vaginal bleeding checked out today. I weakly bleated 'are you… ok?', not really knowing what to say. She said she was okay, but that she was desperate to go and be seen by a doctor, because she was feeling progressively more worried about it and didn't feel like she could wait until her appointment next week to get it seen to. I explained that, for me, going to A&E is a huge thing, to explain my shock. We had a bit of a laugh about this, as visiting A&E was something fairly normal for her. She told me that she was sick of chasing the hospital about something this serious and, after telling a friend what was going on, that her friend had just texted her and told her that she was picking her up at the station and driving her to A&E.

Julie's experiences demonstrate how the biological can interact with the social, and vice versa. What Julie experienced was physical and visceral. She was experiencing abnormal, painful bleeding from her vagina. However, the implications of this bleeding represent what I have described in previous chapters: apprehension to interact with health services until things reached a crisis point, alongside an uncertainty about one's own bodily processes and experience of pain. The example provided above demonstrates why we need to think with and through biology to fully understand the experiences of pain felt by my participants – often pain experiences were mediated and represented through functions of the body. Sometimes, participants felt the only way they could present to health services was when they had 'evidence' of malfunction in their biology.

Furthermore, it is important to consider both sex and gender when considering a) what was happening to Julie and b) why she continued to need to work while bleeding abnormally from her vagina. Julie's experience of these leaky, bloody, visceral bodily phenomena show why it is important to think with bodies while being mindful of how these gendered bodies move through the world. Her experience was simultaneously biological and gendered in ways which cannot be separated. When communicating her pain to me, it was through graphic descriptions of blood leaking from orifices. She understood herself through these biological processes, and made her pain real through the description of them.

However, alongside this, she also spoke of the gendered domestic labour she performed as part of her work. She was highly cognisant of how this contributed to her pain, and often told me how much better her pain would be if she didn't work as a carer. In Chapter Eight, I will refer back to Julie's story to contemplate further how the domestic wage labour she carried out interacted with her attempts to seek support from the welfare state. All of this is tied in further with the expectations placed upon bodies that exist at the intersections of race, gender and class. Julie's experience of pain caused by working was very much still biological – the pain was maintained through working, but was felt and seen in her aching back and swollen fingers.

6.3 What about motherhood?

Being pregnant and giving birth are experiences mediated both by biology and society – they are *biosocial* experiences. The experience of motherhood is something which encapsulates the biosocial experience of pain I have attempted to articulate in this chapter so far. As mentioned in the above section, the act of *giving birth* was often specified to me as not being very painful at all. Similarly, often my participants described being around their children as being pain relieving; smelling their heads, playing with them, and hugging them. Again, this was described in biological terms. For example, Thelma would often tell me how when she breastfed her children, it gave her pain relief. She also, many times, reiterated how hugging her girls, smelling them, and being close to them physically released the hormone oxytocin, which acted as a painkiller for her.

This section will focus on reproductive labour, and how the social experience of *being a mam* induced, maintained and compounded pain. Advice to help manage chronic pain places emphasis on the importance of rest, pacing oneself, and making time for gentle exercise (NHS, 2021). How can this be done when the demands of motherhood take primacy? What happens when the biological and non-biological aspects of motherhood complicate the management of chronic pain? In this section, I consider what it means to be a mother living under a diagnosis of chronic pain, and how the social requirements of motherhood impact the experience and management of pain, right back down to the biological level.

Reproductive labour is a concept that emerged through Marxist feminist thought and activism, cumulating in movements such as the 'Wages for Housework' campaign in the 1970s (Federici, 1975). This movement was concerned with the unpaid aspects of life in the private sphere: cooking, cleaning and childcare. Federici (1975:77) argues that housework 'has been transformed into a natural attribute of our female physique' under capitalist modes of production, once again linking back to the critiques of essentialist ideas about sex and gender. It is not that female biology equips women especially well to care for children, cook and tend to the house, but rather that structural forces dictate that this is what happens. Here, I want to explore how women with chronic pain understand, and sometimes challenge, ideas about reproductive labour.

I argue that the reproductive labour performed by my participants in their capacity as mothers is important to understanding lived bodily and social experiences of pain. It is important to think about reproductive labour not just as an expression of how gender operates, but as being a 'performance' (Butler, 1990). It is entwined with biology and shapes how my participants understood themselves as women who live under the diagnosis of chronic pain. Thinking back to the vignette that opened this chapter, I want to refer to Thelma's words once again '*you know Lucy… dads with chronic pain don't have to deal with this. This is a mam's job, and it doesn't stop just because you're in pain'.* In this statement, there is in implicit understanding that to be a woman is to live in pain. As discussed in the previous section, ideas about biology and biological malfunction formed a key epistemology from which my participants understood their pain. In what follows, I consider how concepts of biology link to ideas about what motherhood 'should be', and how these ideas might lead to the exacerbation of chronic pain states.

6.3.1 Chloe's story

Chloe, a 24 year old woman from a suburb of Sunderland, became pregnant midway through my fieldwork period. She had been diagnosed with fibromyalgia a few years previously, but had expressed suspicions to me multiple times that she actually had EDS (Ehlers Danlos Syndrome) which could be the 'real' root of her chronic pain. In early September 2021, I went to visit her and was especially curious about her experiences with pregnancy so far. She was very eager to discuss this with me. We settled down in her living room alongside her dog. While we chatted, I asked if I could pull out my phone to record her telling me about her experiences, and she nodded enthusiastically. In what follows, I provide excerpts from this conversation, detailing the different aspects of her pregnancy experience up to that point:

3.9.21: Chloe's interactions with maternity services

<u>On telling her GP practice about her pregnancy</u>

Chloe: I filled in a form on the phone with my doctors, and at the bottom it was like 'have you got any health problems?' And I was like yep this, this, this and this. She didn't put any of that on the form! So the form gets sent to the midwife…and the midwife gets in touch around 7 weeks and they ring you, and you have a phone appointment and then they book you in for tests a few days later. And on the phone she was like 'any health problems? On your form it says no'…and I was like 'WOAH WHAT!' And then I told her all me health problems and she was like 'if I'd have known about your health problems, I would have rang you weeks ago put your mind at ease. I just thought you were a nice open and closed pregnancy, so I put you to the back of the list!'. She told me I'd need my hips strapped together later on and I was like what the hell?! The doctors had never put any of this info on, or told me about it.

Lucy: that's so bad! So then… and is it the hyper-mobility or the fibromyalgia that's going to make it difficult, do you think?

Chloe: I don't know, to be honest., they haven't really said. Apparently hyper mobility is good for pregnancy, said the midwife. My hips dislocate and pop out… you can guarantee I'd be lying on that bed and my hip would be over there!

<u>On seeing a midwife</u>

Chloe: yeah so when I went (to see them) they were basically like 'we're so worried about you…' 'why has she.. why have you done this to yourself?' I walked into the room and they sad 'we've been talking about you' and I said… 'yeah I heard'. She said 'were really worried about you… we didn't realise the severity of your illness'…

I was like…. But they didn't ask! They never asked if I was working or to know if I wasn't working because of me disabilities. So then… And then, then… she was like 'you're really gonna struggle, you're probably gonna be on bed rest'. I was like I KNOW, I've done all my research. I know for a fact that when it comes to 20-something weeks I'm probably going to be on bed rest, need me hips strapped together. I haven't done this to myself lightly.

Lucy: yeah

*Chloe: I have really looked into this. I know everything that could possibly go wrong. I know for a fact I'm going to need a C-section, I'm going to request a C-section, my hips will pop out and stuff. And she (the midwife) said 'okay, I just wanted to know that you knew… it's going to be hard. I'm not being nasty but it's going to be really hard'. And I said I know! This is why I've done it now, I'm only 24 - I've done it to myself now while I'm healthy…ish, and can do things still. And this … in mine and Jamie's [*Chloe's partner*] heads we've planned for this to be the only pregnancy, for this to be the only biological child and we're gonna adopt.*

Lucy: Aw!

Chloe: I've wanted to adopt, Jamie's always wanted to adopt… but we… when we started talking about getting pregnant and things I was like 'do you want a biological child?'. For me, I wasn't bothered… I could happily adopt. But Jamie wanted to go through the whole palaver. And I thought ok that's fair enough. And shock… I fell pregnant.

Lucy: was it planned?

Chloe: well we said we'd start trying but didn't expect it to happen straight away! We thought we'd have to go to doctors. We stopped using protection but didn't think it would happen so quick… we didn't even see a doctor! I was like… shit!

<u>On Chloe's choice to not breastfeed</u>

Chloe: I'm not…I'm going to be in a lot of pain so I'm going to want to take painkillers, and you can't breastfeed on them. And as well… I struggle already with not sleeping, being in pain, all sorts. It's one more thing that I have to do - and then. Jamie's mam is really trying to push us into things. But I'm a strong-willed person so I just tell her to fuck off! She's asking why I don't pump, and I say because it's still one more thing that I have to do! I'd have to be attached to a machine for how many hours a day to feed my baby!

Lucy: yeah, you've said you don't wear bras because they're painful right?

Chloe: I've got a crop top on today. It's painful.

Lucy: nearly everyone I've spoken to wants to be a mum or is a mum. It's so interesting to hear the decisions you've had to make for your own health. Like the choice about breastfeeding, you've made to look after yourself.

Chloe: Jamie's sister doesn't understand why I'm not breastfeeding either. And it's like… because it's one more thing I have to do. Jamie gets two weeks off and then he's off on his merry way. He goes to work. And then I'm left with this baby that I have to feed and clothe and look after. And I already struggle to look after myself on a *daily basis anyway. It's a lot. Say my nana comes over for a cup of tea… I could say can I lie down for two seconds, and you feed the baby? It's one more thing off my plate. And it means Jamie can do a night feed, as well. I'm not doing that!*

Lucy: are you looking forward to being a mum?

Chloe: yes so much, so much. Half dreading it though, there's going to be so much and so many obstacles. When it comes to them starting school… it's going to be a nightmare. I know it's a long way off but

Lucy: how do you mean?

Chloe: so Jamie leaves the house about 8am and doesn't get home until about half 5. But I can't walk… I can't drive. like… how am I meant to get them to school?!

Speaking to Chloe at this very transitional time in her life exemplifies the kind of worries that can emerge alongside chronically ill motherhood. These worries were often grounded in biology; about the pain of being pregnant and giving birth, and the pain of potentially breastfeeding. Even the choice to have a baby was a biological one, stemming from her partner's desire to have 'biological children'. Despite not yet being a mother, Chloe was already anticipating the future and worrying about how she would manage her health conditions with a baby to look after. When interacting with health services, her diagnoses, when discovered, had meant that she had been flagged as a problematic pregnancy. Her choice to even have a baby had been questioned. While talking to me, she envisioned her life many years into the future and was already having to anticipate how she would 'cope' in years to come when it came to looking after her unborn child. Although deeply grounded in biology and the mechanisms of her body, the worries about the impact on her health were deeply societal, and were reiterated by health services and family members.

However, she also began to challenge some entrenched ideas about motherhood. For example, she was acutely aware that breastfeeding was likely to exacerbate her chronic pain quite significantly. Making the decision not to breastfeed for her own health had been meet with resistance from her family members. When speaking about her partner, Jamie, she was aware of the inequalities in parenting responsibility that were set to exist between them. This resistance to forms of expected reproductive labour demonstrates further how the choices made by chronically ill mams are a constant balancing act, grounded in what they perceive their bodies can 'cope with'. These worries are grounded in ideas about what chronically ill bodies are able to do, but are mapped within the bounds of reproductive labour.

Chloe's story is a story about her chronically ill body, and the changes it was going through during her first pregnancy. However, the frame of reference Chloe was placed under was that of an expected gendered performance. My participants' bodies were expected to perform femininity in very specific ways, often at odds with their wellbeing. Here, I want emphasise why it is important to think with gender and biology simultaneously; Chloe's story is a story about what her body can physically do, in the context of a gendered performance.

6.4 Living under diagnosis in a gendered body

Chloe's story reminded me of older literature in medical anthropology focused on the decisions often made by mothers when navigating illnesses. Vuckovic (1999)'s 'Fast Relief: Buying Time With Medicines' describes how women make choices with medication to allow them to continue being mothers, wives and carers. Through taking certain medications, at certain times, Vuckovic (1999) observed how women were able to continue performing reproductive labour, even though periods of illness.

Throughout my fieldwork, I heard how these choices were made repeatedly. To manage the functions of their bodies, the women who took part in my fieldwork took medications. However, taking strong painkillers also had the ability to detract from their ability to be a 'good' mam, demonstrating the stigma that can come alongside the ingestion of different medications. One participant, Janet, described to me how her choice to stop taking opioid painkillers was directly related to an experience she had with her daughter. One day, when her daughter was very young, she had found her in the medicine cabinet in the bathroom of their house, holding a packet of the codeine which had been prescribed for Janet's back pain. This experience had shaken her so much, and had made her feel like a *'bad mam'*. As a consequence, she told her doctor she didn't want to be prescribed these medications anymore, for fear that her daughter would get hold of them again.

Repeatedly, I heard from participants how motherhood and the other demands of reproductive labour impacted how they lived under diagnosis. These conversations were focused on the physical pains of motherhood, but also the stresses and strains that came alongside caring for children. Thelma, on my request, would quite often send me texts updating me with how things were going with her and the girls. This happened especially often during the school holidays, when we were unable to see each other in person due to her childcare commitments.

An example of one of these texts follows:

> 'Morning. Thought I'd write and give an account of last night. Dunno if it's any help. Kids aren't good at transition atm yesterday was a rest day for them and cooker still broke. Had to get mam to cook and send food down for the kids cause they wanted foods I couldn't sort without an oven and their sensory is off. They played nice and took meds early, even went to bed early. B fell asleep about 10:30 but G stayed up til 1:30! 5am G was up, had an accident (rare but she'd drank red juice just before bed and was on a rest day so logical that it could happen) but she couldn't process it, she's convinced someone poured water on her bed while she slept. She's been up since 8am. shopping came. B got up at 7:30. Wheels in for repair and it's skippy outside so gonna ask mam if they'll take me to 'n' from work when they collect 'n' drop off the girls. Left leg going crackers, rest of me hurts but not as bad as my leg. Knowing it'll be around 1am before I can sleep again and I'm tired and ouchie today - and have soft play so no doubt will have to rescue B at some point which is gonna smart. But you know, mammy duty, I wanted kids yada yada. Could happily amputate leg today for pain but got too much function in it atm to actually feel serious about it (when it's pretty much paralysed I'd genuinely gladly have it amputated, begged drs many times) hot shower didn't help much. Could happily lie in bed and snuggle Princess but I can't, kids need me 'n' tbh staying still makes it worse. Gotta finish DLA[9] forms today. Exhausting. Can't drink coffee atm hurts my stomach too much, and avoid other caffeine.'

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[9] Disability Living Allowance (an older version of PIP)

This account gives some insight into the ins and outs of chronically ill motherhood. In this text, a number of things emerge: Thelma's domestic situation and broken cooker, the previous night's childcare, Thelma's pain, and finally an insight into how Thelma views her responsibilities as a mother. Her embodied experience of pain, and her need to rest, is always secondary to the reproductive labour she needs to perform. Having children is seen as a choice for which she must face the consequences in the form of extra pain. The pain she is likely to face across the day is a result of *'Mammy duty, I wanted kids'.* This account is another example of how bodily functions occur day to day, and are managed as a chronically ill mother. Thelma's responsibilities as a mum superseded her desire to lie in bed all day with her dog, and furthermore prevented her from managing her pain in the way that is recommended by the NHS. Here, we can observe how gender traces back onto biology, not in the sense of there being any intrinsic link between her pain and her female body, but rather that the gendered expectations placed onto bodies can exacerbate pain.

Expectations placed upon chronically ill mothers are a clear form of gender performance. My participants viewed these performances right back down to the level of biological function; being a 'mam' was naturally to be in pain. This extends from how and when medications are taken, to how and when chronically ill bodies are able to rest and recuperate. As Wilson (2015) argues, biology should be taken seriously, but this is not always in the most obvious ways. Using the examples detailed above, I argue that aspects of motherhood seen as biological by my participants – being pregnant, giving birth, breastfeeding, performing reproductive labour – lay the foundation from which gendered chronic pain states can be magnified.

6.5 Conclusion

The points discussed in this chapter perhaps raise more questions than they provide answers. It has aimed to explore how living under the diagnosis of chronic pain in a gendered body creates biological narratives of what chronic pain is and why it occurs. This chapter does not argue that there is some essential form of 'womanhood' that inherently causes chronic pain, but rather that experiences of living in gendered bodies can contribute to the biological, embodied understanding of chronic pain states. For the women who took part in my research, it was important to articulate pain through these metaphors of biology, in order to make the pain they felt 'real' and traceable in their bodies.

Using various examples from my fieldwork, I have explored how concepts of gender, sex and biology are 'leaky'. The women who took part in my fieldwork often understood their own pain as being mediated through their reproductive function – something inherent in their 'womanhood' contributed to their pain. Their embodied experiences of pain were often visceral, involving the literal leakage of blood and other substances from their bodies. By playing close attention to bodies and biology, it is possible to understand more about how my participants communicate their pain through biological metaphors. As such, it is both constructions of biology and gender which impact how people live under diagnosis.

The embodied experiences of being a 'woman in pain' also interact with broader concepts of reproductive labour, and the expectations placed on women in their capacity as mothers. These expectations were challenged by my participants, but fundamentally there was an acceptance that the demands of motherhood were essentially painful. There was an understanding that being a mother would, and does, worsen chronic pain. This links back to early feminist writings which conclude that in capitalist societies, the responsibilities within domestic spheres have been ‘naturalised’ and are articulated as being a fundamental part of being a ‘woman’. This naturalisation of reproductive labour has led to narratives of a biologically deficient, painful womanhood being created, rather than an understanding that painful biological states are exacerbated by the gendered expectations of womanhood.

The story I have tried to tell in this chapter is complex. The physical act of caring for children contributes to being in pain, but it can simultaneously have pain relieving aspects, as described by Thelma. When conceptualising all of this together, it is perhaps pertinent to think right back to Butler’s (1990) concept of ‘performativity’ – how feminine performances produce feminine bodies. This may go some way to helping us understand how and why the categories of woman, female, mother and pain collide and interact in the ways they do. By thinking about how gendered performances of femininity link back to biological models of pain, this chapter has begun to consider what it is to be a woman living under a diagnosis of chronic pain. By thinking this way, back to anatomy, we can attend to the ‘friction and unpredictability that feminist theories can relish’ (Wilson, 2015: 45). This friction is, I think, apparent in this chapter. The women who took part in my research think about their pain as rooted somewhere in their body, and being linked very closely to the biological functions of being a woman. However, they live under diagnosis in extremely gendered conditions, which in turn serves to exacerbate the chronic pain they feel.

7 Chapter Seven: What Substances Work?

29/9/21 M.H.P.S.G.

Towards the end of September 2021, I started attending the meetings of a new support group – M.H.P.S.G. The group was founded in late 2019, but had not been able to meet during the pandemic. After restrictions lifted, the group had re-formed and had begun to meet in a community centre, a mile or so from the centre of Oceanbridge.

Oceanbridge is a coastal town in County Durham. It has deep historic links to both mining and the military. As I drove across to the meeting, watching the sea loom towards me as I headed down the motorway, I thought about how Oceanbridge is an archetypal 'left behind' town, representing in many ways the way the North East is perceived in the media and popular culture. I let my sat nav direct me towards the community centre, as I had no idea where I was going. I parked up and got out of my car, startled by a couple of large dogs that were jumping up at me from the window of the house next to the parking spot.

Figure 7: The view from the community centre

I walked towards the community centre, noting that it looked very much like every other community centre I'd ever been to, including the centre where Chronic Pain Care was held. It had a wheelchair ramp leading up to it, and leaflets and posters advertising toddler groups, veteran's breakfasts and food banks all over the walls. I quickly found the group, and walked in to take a seat. As with Chronic Pain Care, I was greeted warmly. I explained why I was there, and that I had spoken to Becky, the Facebook admin, about attending. I passed out *copies of my information sheet, explained why I wanted to attend the group, and made sure that everyone in attendance was comfortable with me taking notes.*

Becky then began to explain the ground rules of the group, and I realised that I had actually managed to attend the very first in-person meeting of the group. The purpose of the group, she said, was to meet other people with similar conditions, but not just to 'moan and whinge'. This was said emphatically. She said that she didn't just want to sit there every week and complain, but was hoping to use the group to do craft and relaxation activities, alongside discussing coping mechanisms and supporting each other.

As the group members began to chat to each other, and to me, I noted our surroundings. We were in a very generic room, almost like a classroom. School-like tables, hard chairs and magnolia walls. As we talked, I heard familiar stories of people's pain; how they had engaged with their GPs and occasionally the pain clinic. One group member, Donna, a woman about my age who had joined the group a few minutes after I'd arrived, explained to me that her GP had 'washed her hands of her' and told her there was nothing to be done to help her pain. She hadn't been given a referral to the pain clinic.

The discussion then turned to medications, initiated by my information sheet which gave some examples of commonly used opioid pain medications. A group member, sitting on my left, turned and addressed me directly. She told me that she had 'many conflicting illnesses' - a rare genetic blood disorder and diabetes, to name a couple. As a result, she couldn't take any pain medications except paracetamol. She asked if she was still able to take part in my research even though she 'only took paracetamol'. I said she was, as I was really looking to understand more about life with chronic pain alongside all the opioid stuff.

At this point the conversation picked up, and I felt as though I was being bombarded with the names of different medications. 'I take Oramorph', one group member shouted… 'Codeine for me!' added another. People were speaking too quickly for me to jot down fieldnotes, but I estimated about half the group said they took opioids to manage their pain. Donna spoke about her relationship with her GP again, telling me that they were trying to get her, 'off her pills'. 'It's due to money!' she told me. I asked the group if they had heard about the recent change to the NICE guidelines, which might change how their medications were prescribed, but not many people had.

For the next part of the session, we returned to talking about group organisation and bureaucracy – for example, how to create a good logo and slogan to make people feel welcome, and how to obtain the all-important funding to run the group. This somehow resulted in all the group members telling their diagnosis histories to me, sometimes talking over each other and nodding animatedly in agreement when they heard a story which resonated with them. Becky, the Facebook admin who I had spoken to before, apologised to me about how confusing her story was. 'When I tell a story, I go to Newcastle via Sunderland!' she joked to the group, making eye contact with me.

As the group shared their experiences with pain, this naturally led to a conversation about pain management, with the conversation soon turning from prescription drugs to cannabis. Becky, who lives under multiple painful diagnoses, told the group a story about the pain management advice her son had given her – 'Mam, you just need a big joint!' he had told her. She had tried CBD oil and had found it very effective for a couple of months, until it then stopped working. At this point, Donna spoke up again and told us all that if we ever wanted 'weed', *all we had to do was ask her. She told us how her husband gets edibles (which she called 'eatables') off his friend when he goes to the football. She uses them when the pain is really bad but never smokes weed because of the health implications. Alice, an older member of the group and ex-mental health nurse, interjected to warn the group about the dangers of cannabis. She told a cautionary tale about the cases of cannabis-induced psychosis she had seen while working. I found this interesting, as Alice had offered up quite freely that she took large amounts of opioid pain medications. Similarly, she went on to talk about a time she had visited Amsterdam and tried some cannabis there. I got the sense that parts of her identity as a nurse, and her identity as a person who lives under a diagnosis of chronic pain, often conflicted. Another group member, who had been very interested in the conversation as it progressed, told us about one of her neighbours, an 82 year-old woman who smokes weed and has a 'brilliant time' with it. And so the conversation continued much in this way, concerned mostly with what 'worked' alongside what people 'took'. I noted that, even though I had attended the group to talk to them about opioid painkillers, it was clear that pain management techniques were inclusive of much more than pharmaceuticals.*

The above vignette demonstrates some of the complexities that emerge when thinking about the management of chronic pain with different substances. What is taken to manage pain is inherently linked up with what kind of diagnosis a person lives under. In social situations such as the support group meeting described above, people would often tell me what they 'had' and then follow up with 'what they take', even after I had specified that I was looking to talk to anyone who experienced chronic pain, irrespective of whether or not they took painkillers.

As outlined in my literature review, there is not a huge amount of literature embedded within the anthropology of pharmaceuticals that focuses specifically on the use of *prescription opioid painkillers.* Work on opioids and other potentially additive painkillers tends to be situated firmly within the anthropology of drugs. In this chapter, I look to both the anthropology of pharmaceuticals and the anthropology of drugs to think about how my participants managed pain using various different substances. In the above vignette, it is clear that knowledge around painkillers is focused on a) what can be accessed easily, and b) what is effective. Whether or not a substance is legal or illegal, or whether it is an opioid or not, holds less importance. Conversations about prescription opioids at support groups often segued into conversations about cannabis, which is a class B drug in the UK. As I spoke about drugs with the women who attended M.H.P.S.G., it became clear that concerns about pain management were mainly centred around 'what works'. Both prescription medications and other (illegal) drugs, were used in very idiosyncratic ways by my participants. This chapter will discuss these idiosyncrasies – how people manage their pain is not dictated by what is legal or illegal, prescription or non-prescription, or opioid or non-opioid, but by what provides relief. In this chapter, I explore the use of prescription opioids, alongside the use of over-the-counter (OTC) medications and illegal drugs, to manage chronic pain.

For the reasons stated above, I have decided to forgo a focus on categories of legal/illegal or prescription/non-prescription as key epistemologies. By referring to painkilling 'substances', I aim to prevent the distinctions I have described above from limiting my analysis. The processes of 'taking substances' contributes to how pain is felt and navigated, day to day. This approach links backs to the focus on biology taken in the previous chapter – however, in this chapter I focus on what substances people use, when they use them, what they do to a person's body, and how those effects are felt in the body.

To structure what follows, I draw from Geest *et al.,* (1996) to explore how these substances are accessed, stored, circulated and consumed in the everyday. I consider the effects this consumption has on the bodies of those who take them. This chapter is split into three main sections. I look first at access to two different substances: Co-codamol and cannabis. Neither of these substances are routinely *prescribed* for chronic pain, but are used in different ways in order to manage pain levels. Secondly, I look at how different substances are stored. By doing so I demonstrate how these substances are used to shape the everyday; there are expected patterns of use that come alongside the taking of different substances, which are part of their efficacy. In order to 'work' different substances need to be taken regularly, and as such they change the way time is experienced. Finally, I look to how substances are ingested and absorbed by my participants. I look how models of efficacy were once again described by biological models. After ingestion, participants 'felt' efficacy through the careful monitoring of the substance's effects on their bodies, regardless of whether the substance was being taken according to medical advice, or not.

Rather than considering how medications are taken as being pre-defined, I consider these substances as being situated within, and being 'made up' by, different orientations of space and time. In the words of Hardon and Sanabria (2017), they are 'fluid'. It is well documented that the taking of substances is a key aspect of the management of chronic pain in North East England (Mordecai *et al.*, 2018; Alenezi, Yahyouche and Paudyal, 2021). In this chapter, I argue that these substances (and what they do to people's bodies and pain states) are used and understood in very specific, often curious ways. They circumvent expected patterns of usage, and as a consequence shape the form of the everyday.

7.1 Access to substances

As has been discussed throughout this thesis, access to prescription medications was often, but certainly not always, facilitated by a doctor. Accessing medications this way is often the 'expected' pathway a pharmaceutical might take (Geest *et al.*, 1996). After a prescription is issued by a clinician, medications are then collected from a pharmacy and taken to their point of use (often the home). Although theoretically a simple process, in reality it becomes complicated by multiple factors that can disrupt the doctor → prescription → patient pipeline. This is why using this biographical approach can be so enlightening – it allows us to highlight the interesting practices and interruptions that occur alongside, or in place of, expected processes of pharmaceutical flow.

In the case of my participants, these interruptions were ever-present in the stories I was told. Sometimes, repeat prescriptions were left unmonitored by a participant's prescribing clinician for many years. This resulted in some of my participants accumulating vast amounts of opioid painkillers. Ella (whose diagnosis history was told in Chapter Four), had over 100 tramadol pills stored in her bathroom cabinet. She showed these to me over Zoom as we talked about how and when she took her medications – for Ella, the tramadol tablet held a specific meaning, and was used to facilitate access to certain state resources, which will be discussed in the next chapter. Ella revealed to me that the medications, which she had been prescribed to take four times a day, were actually taken on an 'as needed' basis.

Similarly, sometimes supply chain or prescription issues meant that doses of drugs were not able to be accessed at the right time. This can be seen by Thelma's experiences with her nabilone prescription in Chapter Five. As a response to her (correct) worry that her consultant would one day lower her dose, Thelma had simply decided to stockpile her medications and take a lower dose of the nabilone over a longer period of time, in order to ensure that she could maintain access to nabilone for as long as possible.

As my fieldwork progressed, it was very clear that prescription drugs were important, although not always used exactly as intended. However, many participants reported being unsure about taking prescription painkillers (normally based around perceptions of the 'strength' and implicit danger of these medications), and therefore opted to use over-the-counter, 'safer' medications to manage their chronic pain. Furthermore, access to illegal substances such as cannabis formed a part of some of my participants' pain management strategies. Here, I explore access to both OTC medications and cannabis, in order to re-emphasise that viewing pain medication using the 'prescription-or-not' dichotomy is unhelpful. By exploring what is taken outside prescriptions, I aim to emphasise why following substances around is so important to try and understand how people access pain relief.

7.1.1 Co-codamol

Co-codamol is an analgesic constituted of two commonly used medications: paracetamol and codeine phosphate. It comes in three different strengths, the lowest of which (8mg of codeine combined with 500mg of paracetamol), is available to buy over the counter in the UK under the supervision of a pharmacist. It can be sold for the relief of acute pain which cannot be relieved with paracetamol, aspirin or ibuprofen alone (NHS, 2018).When purchasing this medication, the patient is to be advised not to take it for any longer than three days at a time.

The landscape of co-codamol use in the UK is fundamentally unregulated. If looking to buy significant amounts of the medication, it would be feasible to visit multiple pharmacies and obtain multiple 3-day supplies of the drug. During my fieldwork, this was something that was reported to me multiple times. One participant, Sophie, told me the story of what happened when she had visited her doctor in her late 20s complaining of chronic pain and relentless fatigue. These symptoms cumulated in a fibromyalgia diagnosis:

'She… I'm trying to think which medication I got prescribed first. I think it was co-codamol. I … she kind of said, 'What have you been taking?' and I said, 'paracetamol and ibuprofen'. She said, 'Do you want to take codeine?' And… I didn't know much about medication… I can list what I've been on and what they're for, but I don't necessarily know. I'm not a doctor, I don't know all the medicines. I had heard of codeine before though, I think my mum had mentioned it before. So, I asked the doctor, 'isn't it quite strong?' And she said, 'it doesn't have to be if you have a low dosage… it's not a massive leap. It's not like I'm putting you on morphine or anything like that'. And I was just like… 'I don't know if I feel comfortable taking it'. And she was like, okay… what about co-codamol?', and I was like, 'what's that?'. Obviously, now I can list them and know what they're for, but back then… I was like… I knew paracetamol and ibuprofen. And she said, 'it's like a combination of codeine and paracetamol – you're kind of bridging the gap rather than jumping straight from paracetamol to codeine, you're mixing the two together. You can buy it over the counter'. And I was like, 'okay… so… can't be that strong if you can buy it OTC?… If you can buy it over the counter… how bad can it be?'. Looking back now I'm like… ugh! But, that was the process - if it's prescribed - ugh! but if you buy it… it must be ok. You can buy paracetamol for 16p, so it must be fine.'

As the interview progressed, Sophie described to me how she had begun taking the co-codamol and, although it didn't work brilliantly, had worked enough that she had progressed to buying more packets herself from her local pharmacies, to ensure that she could keep taking it day-to-day. After that she returned to the doctors with some concerns that she was becoming addicted. She described the following encounter to me:

'I started to notice that I was buying boxes of it. Two or three boxes a week. And I can't remember a day when I didn't take it… I took it at least once a day. Some days I would only take one dose, but others I'd take the full 4 doses. The box was lasting 3 or 4 days maybe, and then I was needing another box. I was like… I don't think I should be taking this. It's not really working and I'm spending an absolute fortune. I felt a bit like I was doing something wrong. Obviously, on the box it says don't take them for more than 3 days, but I was like… alternating the shops I was getting it from because… if you got it from a chemist, they'd ask you, 'have you had these before?', and I'd say 'yes,' 'have you had them in the last week?', and I'd be like… 'No,'…. (While thinking, yes, I'm already on my third box this week!) but I'd say, 'no, I haven't had them yet this week,' (yes, I have!). I did this for a couple of months and I thought, you can't keep doing this, it's not good. So, I went back to the doctor. This was doctor number 5 I think…. yeah. It was a female again, different to doctor 4. I went back and I said, 'I saw your colleague a few months ago, they recommended co-codamol but I've heard nothing from them and we're months on. I'm getting through 2.5 boxes of co-codamol a week and I'm pretty sure I'm not supposed to be taking them.' And she was like… 'No, not really, we don't want you taking them that much. If you are, you're either starting to get addicted to the codeine, or… you're actually in significant amounts of pain and it's not working and you need something different.' I was like… I don't like either of those answers! I don't want to be addicted to drugs at 26. I also don't want anything stronger… I don't want that!'

After talking to her GP about her co-codamol use, Sophie was prescribed naproxen and pregabalin to help manage her pain, while she was waiting to be seen by a consultant regarding a diagnosis.

'In the September, I went to the RVI [a large hospital in Newcastle]. *I saw… I can't remember his name, a male doctor, and he asked me to tell him the full story of how it all started - the tiredness, the naps, the general sensations. And he… again… was like, 'I think its fibromyalgia''*

From here, she was referred to a pain clinic where she was offered a 6-week psychosocial support program, alongside the medications she had been started on by her GP. She described her feelings about this:

'On one hand - great! I want to get off these tablets, but on the other hand… these 10,11 tablets are the only thing getting me through the day.'

From Sophie's experiences, it is clear to see that access to medications is not straightforward. Often, prescriptions carry through from previous appointments with health professionals, and logics and knowledge around medication strength emerge from encounters with GPs. Beliefs around the strengths/safety of medications and how they act on the body are often created during the clinical encounter, but the pharmaceuticals themselves are often accessed outside of the prescription chain. Regardless, access to medications was facilitated, and maintained, by health professionals. Even though Sophie was obtaining her co-codamol over the counter, the way she took these medications was ultimately decided by her GP. This is much in line with the anthropology of pharmaceuticals, which views 'prescription' as a key stage in the social life of any pharmaceutical. However, the important aspect of this prescription stage is perhaps more aptly represented by the beliefs that are created about different substances during clinical encounters, and what they do to bodies during this time.

Prescription was not the only way that pain medications were accessed by my participants. Mandy, who is in her 50s and works full time, described to me in detail how she accessed her pain relief. She lives under the diagnosis of fibromyalgia, but had had very limited contact with her GP since she was diagnosed by a rheumatologist in late 2019. A combination of lockdown and working a 9-5 job had meant that her options to visit her doctor had been quite limited since her diagnosis.

Lucy: So did having that fibromyalgia diagnosis, did it help you access care through your GP?

Mandy: (shakes head) I'm guessing I could have pushed it. I wasn't sure if I was meant to go back to my GP and say, 'I need this'... but to be honest, I've been registered with that doctors' now for, I'd say… 4 years. I haven't seen any of them in person, that's before lockdown. You have to get past the receptionist… obviously I'd saw the guy and I spoke to one doctor about my fibro once on the phone and then I spoke to... another doctor about allergy problems? I just bought co-codamol myself over the counter, because I can't take anti-inflammatory meds. I'd read up a canny bit on amitriptyline… and what's the other one they normally give you? Um, they give you… there's a couple of painkillers/antidepressants that seem to get recommended.

Lucy: Duloxetine?

Mandy : That sounds about right. I read up on those ones and thought, I don't fancy that at all, to be honest. I used to be on antidepressants for years, I was on fluoxetine. I came off them for a reason, didn't want to be on them anymore. So, I didn't want to go that way.

Lucy: So, do you have anything prescribed at the moment?

Mandy : Nothing prescribed, no.

Lucy: So it's just OTC stuff – that must cost a fair bit?

Mandy : (Laughs) yes…it was… I really started cutting them down you know. I think it got to the point where I was getting quite reliant on them, if I'm being honest, to the point where one of me friends, who I'd went on holiday with, had a word with us. She said, 'you seem to be awfully bothered about how to get to a chemist! If I'm being honest!'. My other half was like… he's… he doesn't take any painkillers and he just said, 'I think you're getting quite reliant on those, mind', and I was, I was taking 6 every day I would say. I never went above 8 because I'm a right rule follower! But, I think it was 6 every day. I started cutting them down myself. Normally, now I take 2 a day, 2 every other day maybes.

The two examples discussed above demonstrate how the same compound – co-codamol – was accessed in divergent ways. Sophie was advised to take it by her GP, and was initially given it on prescription. But, after accessing it herself OTC in a way that was concerning to her GP, she was switched to different (prescription) medications. Mandy circumvented any contact with her GP and accessed her co-codamol directly from the pharmacy to begin with. Both women interviewed were aware of the potential for addiction which came alongside this medication, but felt it safer to use than other prescription drugs due to the fact it can be purchased OTC.

7.1.2 Cannabis

Access to medications was not just complicated by the use of over-the-counter medications for pain management. As discussed in the vignette that opened this chapter, access to illegal substances, such as cannabis, formed part of living under a diagnosis of chronic pain. Knowledge about the pain-relieving properties of this substance was communicated through support groups and communities, despite its technically illegal status in the UK. Participants learned from each other the different ways that cannabis (and indeed, cannabis derived products such as CBD) could be used to ease their pain.

On a Zoom call with Chloe in March 2021, I discovered more about how both pain medications and illegal drugs circulated around her tight-knit community. In this setting, there are few distinctions between what is prescription and what is not, but the focus is on what can provide relief when taken. We were discussing a recent flare up she had experienced, and she told me that she had taken some co-codamol before calling me. After the call, I took the following fieldnotes:

Fieldnotes, 31/3/21

We talked a bit about the flare up Chloe had over the weekend. It arose because she couldn't sleep on Thursday night, this lack of sleep led to her staying in bed until yesterday morning. She only got up because she had to make biscuits for her aunt's birthday (community thing again!). I asked her if she was feeling better and she said, 'no!'. She'd taken codeine before she came on the call. She corrected herself at that point and said that it was actually co-codamol because she's had such difficulty getting hold of codeine from her GP. The stuff she took was a bottle given to her by a grandad figure in her life (but not a blood relation) – he gave her it to use on an 'emergency' basis. She said, for her, co-codamol isn't as good as codeine, even when the codeine is at the same dose. I asked what benefit she'd got from the co-codamol, and she said, on her pain scale it had taken her down to a 6, which is her baseline pain. I decided to be cheeky and press her on what she knows about the circulation of pills in the community: she told me she knows plenty about drugs but not much about prescription pills. Her dad has been suffering a lot with his back and has been taken off his pain meds, so the boys who live up the road (she described them as wrong un's, drug dealers), have been dropping round 'spliffs' every so often to help her dad with his pain. This really emphasised the kind of care which emerges in this community – someone who had been described as 'wrong un' provided pain relief when it was denied by a GP. The same family have also fixed Chloe's boiler before – she knows them well enough to trust them, she explained to me.

Access to cannabis came up multiple times throughout my fieldwork, in surprisingly open spaces such at the support group meeting I described at the start of this chapter. There was a consensus that cannabis was effective at managing pain, and as a consequence participants were open about how they accessed it. In some cases they even facilitated access for others. Some participants had even been told by their doctors, strictly off the record, to try smoking some 'weed' to see if it helped with pain. At one of the first meetings of Chronic Pain Care I attended, I had a very candid conversation with a new member, Tina. We were sitting across from each other, which meant that the entire group was able to hear what we were talking about:

Fieldnotes, September 2021

Tina, the younger woman, told me that she had visited the pain clinic and her consultant had told her, off record, to smoke 'weed' to manage her pain. The medicines she had been given to manage her pain weren't working. She told me that when she looked in the mirror, she thought that she was dying. But still, she was reluctant to smoke cannabis. She said she was completely shocked by the consultant, as she didn't want to do anything illegal. She had refused. She didn't want to 'do drugs.' One night however, she had tried it out of desperation. She had been in excruciating pain and her husband had gone to pick up a 'spliff' for her to try, begging her to try anything that might help. She described what she felt after she smoked the joint, as 'instant relief'. She looked at me and said, 'it's frightening how quickly it takes the pain away.' After that, she began to smoke a very small amount of 'weed' every night until one night, she had a bad experience and felt very sick. That, combined with the fear of smoking 'weed' around her stepson, meant she did not want to continue accessing cannabis illegally. We talked about the potential for cannabinoid drugs in pain management, and she emphasised to me again just how much it had worked, and how she hoped that painkillers derived from cannabis would be accessible to her in the future.

The two examples given above demonstrate how community networks are utilised to access forms of pain relief far outside the bounds of prescription medicines. Using the example of cannabis, we can consider how painkilling substances are accessed, regardless of their intended 'purpose'. By expanding the category of 'access' to being to any kind of 'substance' used for healing purposes, it is possible to understand further the practicalities of pain management in North East England. More often than not, pain relief (both theoretically and practically) came from within the community, rather than the clinic. The idea of 'self-sufficiency' regarding treatment and support for chronic pain will be discussed further in the next chapter. Here, it is important to note that contact with physicians regarding access to pain relieving substances did not constitute a large part of the everyday experience of living with chronic pain. Instead, knowledge about substances, and access to them, came through the community.

7.2 Storage of substances

Storage represents a transitionary stage between the 'distribution' and 'use' stages of the biographical approach to pharmaceuticals (Geest *et al.,* 1996). During my fieldwork, I observed how the storage of substances impacted upon my participants' experiences of time and space. Often, the way medications were stored emphasised the perceived risk, or danger, associated with a certain substance. For example, many participants were explicit about their desire to keep medications in a safe place, where children or pets could not access them, referencing the 'strength' of the drugs they were on. Conversely, other participants left their medications in obvious places, or carried them with them in handbags, to facilitate easy access when needed. While living under diagnosis in the everyday, participants placed a lot of importance on having medications accessible to them in the home. Many participants expressed worries to me about getting 'stuck' without easy access to painkillers, and so made sure there were a few accessible in each room of the house. To know where medications are is to have some control over the present, and to be able to anticipate problems in the future.

While doing fieldwork, I made a specific effort to ask people where and how they stored their medications. Often this question was met with surprise, but then participants became keen to share with me how they organised their medications. During the 2021 lockdowns, I asked participants to show me where they kept their medications in the house, while we were texting or on a call. Boxes, full of pills, were held up to laptop cameras so I could look inside. Numerous photos of different medications were sent to me over WhatsApp. I was taken (via webcams) to bathroom cabinets where hundreds of blister packs of opioids were stored. Later, during in-person research, I was shown organised packets of painkillers in kitchen cupboards. At support group meetings, I saw painkillers being slipped out of handbags and swallowed while conversations continued.

One hot day in June 2021, I visited Ivy at her house. We were sitting outside stroking her cat and drinking huge cups of coffee. We had been talking for hours and had got onto the topic of her memory, and her ability to remember to take her meds. For her pain, she was prescribed pregabalin alongside a weekly buprenorphine patch. Buprenorphine is an OAT which can be prescribed both for addiction to opioids, and also for the long-term management of chronic pain. It comes in patch form, which Ivy stuck to her skin and kept on for seven days at a time. I took the following field notes while we were talking about remembering to take medications:

Fieldnotes, 10/6/21

I asked Ivy where she keeps her medications, as I had been wanting to do this for a while. We sat and sipped our coffee, and she told me about how she keeps nearly everything she takes in the fruit bowl in the kitchen, as this helps her avoid forgetting to take them. I had already seen the meds in the fruit bowl while she made me a coffee, and had noted absent-mindedly that it was quite an unexpected place to keep pills. On a night-time, she will leave out what she wants to take in the morning, so as not to forget. At the moment, she also leaves a Covid testing kit out on Mondays and Thursdays too, to help her remember to do the test on Tuesdays and Fridays. I asked what she takes with her when she leaves the house, and she told me she only takes paracetamol. The medications she takes are regular meds, which need to be maintained by regular dosages. When she needs a top up of painkillers, it can only be paracetamol. But again, the taking of the paracetamol out and about with her, is very much on a 'just in case' basis, and she always wants to make sure she has it on her.

By looking to how medications are stored, it is possible to see how the contours of chronic pain management shape a person's day. Ivy's medicine storage shows how the use and efficacy of substances is very deeply entwined with time and how it is experienced. She keeps her medications in the fruit bowl, rather than in a specific medicine cabinet. This allows her to remember to take them at regular intervals, as she sees the fruit bowl every morning when she wakes up and makes a coffee. Every evening, she leaves out her medications for the following day; there is an expectation of what she will take, and when. Through Ivy's medicine storage, it is possible to see how the storage of medications in the home has a predictive quality. Every day, Ivy expects to get out of bed and pick up her medications from the fruit bowl in order to take them, and keep the levels in her blood stable. The future – what tomorrow might be like, and what readable level of medication will be in her blood at any given time – is predicted through the way her medications are stored.

For Ivy, where she stored her medications influenced how well they worked, because she was able to remember to take them in a systematic way. Understanding how people organise the substances they take in order to remember to take them, or to ensure a constant level of substance in the blood, is important to the reality of how substances work. For my participants, painkilling substances were deeply embedded in everyday lives, and extended into people's homes and people's belongings. The storage of different substances allowed for pain to managed predictably, even when the pain felt in a body on any given day might be unpredictable.

7.3 Ingestion, absorption and diffusion of substances

Fieldnotes, September 2021

I visited Chloe in September 2021 to talk to her about her pregnancy. A key issue that emerged was how she would manage her pain while pregnant, as she had been told to avoid opioids while gestating. After we had finished talking about her experiences with pregnancy services, I stopped the recording and turned the conversation towards how she would manage pain without opioid painkillers. It seemed like a chance to have an interesting conversation. I knew her dad had been smoking 'weed' to help his chronic pain so wanted to delve a little more into her thoughts on the topic. She told me her dad had just started trying something new – dope butter! Her dad buys it from one of his friends – it's essentially cannabis cooked into coconut oil, which is then put in a large syringe, squirted into the mouth as needed and swallowed. Her dad has been taking small amounts throughout the day to help his pain. She also has an aunty who has chronic pain after being diagnosed with a rare cancer several years ago, who swears by the same thing. It's her uncle's friend who makes it. I asked her if she'd ever thought of trying it and she said she's going to once she isn't pregnant anymore. Her dad got the syringe about the time she 'fell' pregnant, so she wasn't properly able to try any of his. They were waiting until she had a bad flare up so they could properly test it, but the pregnancy happened before.

The substances used by participants to manage pain were ingested and absorbed in multiple different ways: they were swallowed as pills, patches were applied to the backs of arms, injections pierced the skin, cannabis was smoked, eaten or squirted into the mouth. How these substances were used demonstrates the many ways painkilling substances work their way into, through and out of bodies. Following Hardon and Sanabria (2017) and Wilson (2015), this section will follow what happens to the painkilling substances used by my participants as they permeated bodily boundaries, and were then felt to act on (or were acted upon by) nerves, organs and cells. This section demonstrates the different understandings that exist about how painkilling substances pass through the body, and what effects they have.

10/6/21 Fieldnotes from coffee with Ivy (continued)

I asked Ivy if I could see a Butec patch, as I've not actually seen one before. 'Of course!', she said. She showed me the one she was wearing at the time – she stood up and lifted up her dress, showing me a small square shaped thing, which looked like a plaster, underneath her armpit. I could see the word 'Butec' written in small letters on it. She told me that the inside of the patch looks very much the same – like plastic. I asked if she always put the patch on in the same place, and she told me that she alternates, as the skin underneath and around the patch can get quite itchy and irritated. Every time she puts a new patch on, she puts it on the opposite side of her body, and she always puts it in a slightly different place each time. We talked about how weird it was that she is prescribed buprenorphine, and wondered if it was due to her intolerance to codeine and tramadol. As an ex-nurse, she understood well the usual use of this medication. We talked about how buprenorphine is also an OAT. She told me how, when she was prescribed it initially, she was told it wasn't addictive. 'Mind…' she said, 'I was also told pregablin wasn't addictive either.'

Ivy's knowledge around her patch is very specialised. From her experiences with it, she knows to apply it in a different place every week, to avoid her skin becoming sore and irritated. As I got to know her better, we communicated about her pain using language focused around the patch. Ivy told me that her pain relief was dependent upon whether the patch stuck to her skin 'well'. Consequently, time became split into 'good patch weeks' and 'bad patch weeks': a good patch week was synonymous with feeling well, whereas a bad patch week meant feeling large amounts of pain alongside some slight, but nonetheless unpleasant, withdrawal symptoms. Efficacy was centred around whether or not the patch had stuck to her skin, allowing the pain-relieving buprenorphine molecules to be absorbed through her skin and into her bloodstream.

Similarly, many other participants had models of efficacy that revolved around understandings of how substances were absorbed into, and acted upon, their bodies. When discussing the swelling of her legs which came as a consequence of her CRPS, Thelma explained to me (via text) how taking her Nabilone helped with this:

> Thelma : its just the edema from CRPS. Cannabis reduces inflammation 'n' puts an artificial coating on the myelin sheath (of course I'm not a doctor so when I say such things to doctors they dont listen and wonder if I even understand the words I'm using).

Through explanations like this, it is clear that participants were constantly engaging with biomedical models of the body and understandings of how substances acted on their biology. Rather than just taking the medications they were prescribed for pain, detailed models of efficacy existed. These models were focused in on actions at the cellular level, and were used by participants to explain why they took the substances they did, when they did. Furthermore, close attention was paid to bodily processes when describing what absorbing pain medication felt like:

18/5/21 Fieldnotes, walking with Ella

We moved from the field into some beautiful woods, which I took a picture of. I asked if she was looking forward to her new job starting and she said she was, but she'll be sad to leave her friends. She changed the subject and again apologised for how bad her brain fog was today – she'd taken tramadol again. When she takes tramadol, she told me she calls it going on her 'dolly holidays' and she becomes 'dolly daydreams', hardly knowing where she is or what she's doing.

We got to the top of a huge hill and Ella looked around slightly confused, worried she had taken us the wrong way. She eventually found where we needed to go to and we walked along the tops. She said that it was probably good for me to see her on such a confused day, and I agreed, telling her how I would like to write this up as part of my ethnography.

At this point we were staring down over Gateshead and Newcastle, and Ella told me about the way tramadol has been making her feel, giving examples through the kinds of things she experiences when taking it. We stopped and she showed me the Fitbit app connected to her phone, demonstrating to me the weird, disrupted sleep she has when she takes tramadol. She told me how this morning she woke up at 4am, feeling stoned, and had just laid in bed smoking her electronic cigarette for half an hour before going back to sleep. She had taken *a tramadol at about 11pm the night before, and sat around texting all her friends before going to bed – again describing this feeling as 'drunk texting', or as being stoned.*

Ella, who rarely took tramadol, paid close attention to what it did to her body when she did take it. The metaphors and phrases she used – 'dolly holidays' and being 'dolly daydreams' – invoke feelings of sedation and distance from reality. However, she was aware of the impact of the medication she had taken and what it did to her body, pointing out to me several times during the walk instances where she felt she was acting abnormally due to having taken tramadol that day. Similarly, she had been using an app on her phone to track her sleeping in order to 'see' the effects the drug was having on her. By doing so, she showed me, using numerical data, the differences between her 'tramadol self' and her 'normal self'.

Through the examples presented above, it is possible to see the knowledge about bodies and efficacy that emerge when different substances are used to manage pain. As Hardon and Sanabria (2017) argue, efficacy does not begin and end when the pill is swallowed. Instead, the body needs to be viewed as porous and part of an environmental system of exchange. For my participants, an awareness of the passage of substances through the body is felt and attended to until the effects of the substance pass through or exit the bodily system. For Ivy, this passage was sometimes impeded by the delivery system of the buprenorphine patch not adhering to the porous boundary of her skin properly. For Ella, the effects of the tramadol she took to manage her pain could be 'seen' via an app on her phone, many hours after the pill which delivered it to her stomach, had been swallowed.

7.4 Conclusion

Living under diagnosis in the present involves considering the movement, storage and ingestion of various painkilling substances. These substances are not just pharmaceuticals prescribed for painkilling purposes, but involve an abundance of different molecules, accessed through both licit and illicit routes. By thinking about these substances, this chapter has addressed the idiosyncratic ways people manage their chronic pain as they navigate daily life. The word 'substances' is used throughout this chapter to describe the 'materia medica' (Whyte, Geest and Hardon, 2002) used by participants to manage their chronic pain. By engaging with literature from within the anthropology of pharmaceuticals and the anthropology of drugs, I have attempted to demonstrate why drawing boundary lines between these categories is not productive when considering painkilling substances. Instead, we need to follow Hardon and Sanabria (2017) and Wilson (2015) and consider how these substances move around to understand how they work.

To do this, I have drawn again from the anthropology of pharmaceuticals to consider different aspects of these substances' 'social lives' – access, storage, and ingestion, consumption and diffusion. Firstly, I have used ethnographic examples and interview data to show that the substances used to manage chronic pain are not just prescription drugs, but instead involve many different molecules which relieve pain. Knowledge about the potential efficacy of these molecules is accessed both via doctors and far outside clinical settings. Throughout my fieldwork, I understood that 'illicit' or 'unofficial' substances were as important to pain management as the medications prescribed by doctors.

Secondly, these substances shape the experience of time in the everyday. Painkilling substances are temporal markers – they allow people who live in pain to jump forward in time and expect something about the future.

Days are often spent waiting until it is ‘okay’ to take another pill, or sip more cannabis butter, or apply another buprenorphine patch in the hope that it will diffuse through the skin efficiently. Swallowing, applying, drinking and smoking these substances punctuates and structures time, allowing people who live under a diagnosis of chronic pain an element of predictability in an otherwise unpredictable everyday.

My participants were acutely aware of the passage of these substances through their bodies, and were able to track and describe what happened, and what these substances did, far beyond the point of ingestion. By using ethnographic examples focused on how substances are consumed and efficacy is experienced, I have shown how my participants felt painkilling substances work their way into and through their bodies. By monitoring themselves and playing close attention to their bodies, they were able to measure and understand the effects these substances had on their pain.

Using painkilling substances was an integral part of living under diagnosis. Most, if not all, used substances in one way or another to allow for periods of relative comfort and furthermore, allow them to ‘function’ day to day. Many ideas and idioms existed around what these substances did to their bodies, and how the use of different substances was warranted and could help to facilitate ‘good days’ or even ‘good weeks’. Thinking about ‘what substances work?’ forms a key part of the everyday experience of living under a diagnosis of chronic pain.

8 Chapter Eight: Biocitizenship, Traumatic Landscapes and Access to State Benefits in North East England

In this chapter, I consider how forms of biocitizenship play out in the 'traumatic landscapes' (Proudfoot, 2019) that constitute parts of North East England. By doing so, I highlight the links that exist between individuals who live under a diagnosis of chronic pain, and the British welfare state. This chapter looks at the importance of place to life under diagnosis, by exploring how biocitizenship occurs in areas of low resource and high demand.

This chapter consists of three main sections. Firstly, I explore how biocitizenship comes into being in the North East. Drawing from Petryna's (2002) *Life Exposed* as a key ethnographic text, I provide a comparison with my own findings from the field. Here lies an important caveat – North East England is not Chernobyl. These two locations have different histories, populations, health concerns and economies. However, in this chapter I draw parallels between Petryna's work and my own, in order to understand further how biocitizenship unfolds in the North East. It provides a framework through which I consider the links between sickness, place and access to state resources.

After considering biocitizenship in the North East, I reflect on the forms of industrial and post-industrial damage specific to the North East that shape the places where my participants lived. To do this, I use Proudfoot's (2019) concept of the 'traumatic landscape' to demonstrate how place shapes the everyday experience of living under diagnosis. In the North East, there are long histories of post-industrial neglect and decline – clear examples of the structural violence discussed at length in this thesis. The patterning of various health inequalities in the North East (including chronic pain) have been linked both indirectly and directly to this decline. This occurs both through the risk to health that living in post-industrial landscape brings, and also through the lack of resources that exist for health and wellbeing in the area. This emphasis on context is important. This chapter foregrounds place when thinking about how biocitizenship works in the North East.

Finally, I consider *how* biocitizenship was used by my participants to access state welfare benefits. I ask how people in the North East try to access resources, in a place where there are few. As with Petryna's interlocuters, part of biocitizenship for my participants was oriented around the evidencing of 'biological damage' as being the direct cause of long-term pain and disability. The need to do so emerged from living in an area where resources were scarce, and the needs of the population were high. However, in 1990s Ukraine, this biological damage was evidenced through proving exposure to certain levels of radioactive materials which occurred in a geographically defined area. As I will demonstrate in this chapter, my participants did not have to directly link the traumatic landscapes in which they lived to their poor health in order to obtain benefits. Instead, they needed to provide evidence of biological damage through performing the 'right' kind of sickness. Performing the 'right' kind of sickness was learned through experience, and through encounters at support groups.

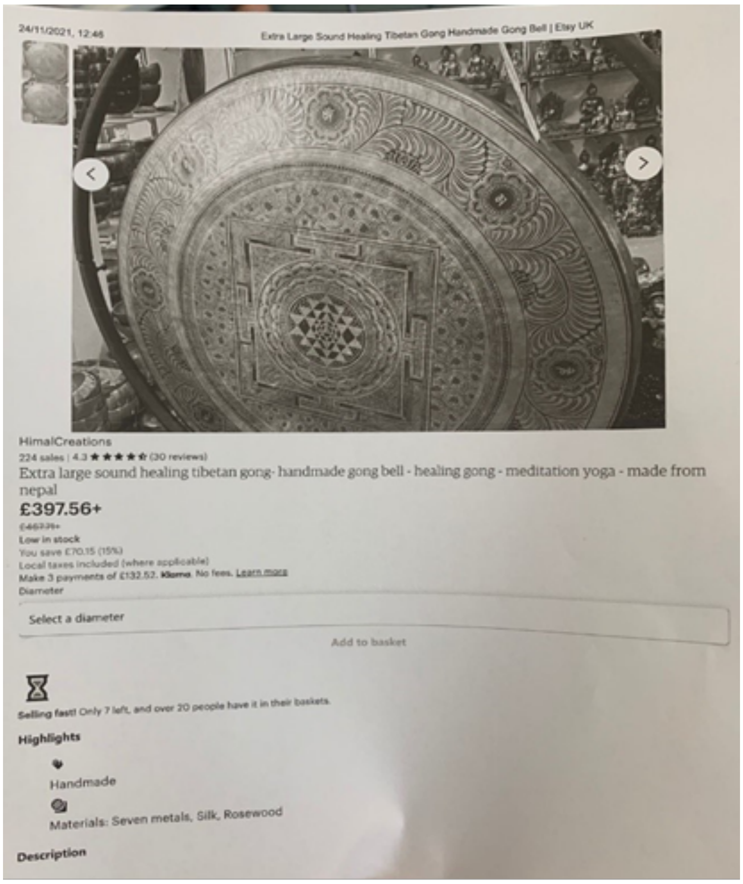
This chapter demonstrates what it is like to live under a particular diagnosis, in a particular place. The North East has specific social, political and historical characteristics which allow it to be described as a 'traumatic landscape'. By applying this understanding of health and place, and contrasting it with Petryna (2002), I aim to further demonstrate why participating in biocitizenship is such as important part of life under diagnosis in the present. I explore what it is like to be disabled and/or chronically ill in an area of high deprivation and low resource (Tudor Hart, 1971; Mercer *et al.*, 2012). For my participants, the state provided little in the way of support and care for their chronic health conditions. Instead, they turned to support groups in order to build social networks, and find ways to obtain support for their illnesses.

8.1 Biocitizenship in North East England

M.H.P.S.G. 1/12/21

The weather over the last few days had been semi-apocalyptic. Storm Arwen had hit over the weekend, bringing with it a red weather warning to stay inside, and significant amounts of damage to local infrastructure which was already long overdue some work. I was slightly nervous to drive over to the coast to attend M.H.P.S.G, as I had heard the damage along the coast had been notably worse than inland. As I approached the community centre, it was still raining hard and visibility was poor. I parked nearby and walked up to the centre, taking stock of the surroundings as I had got into the habit of doing every week. The centre was decked out in Christmas decorations, with bows tied around the doors and a Christmas tree in the foyer. Out front were boxes of root vegetables waiting to be taken by anyone who needed them. As I walked inside, I saw, as usual, a huge box full of donated Greggs pasties on the table – they were there for anyone who was hungry, with no questions asked.

Becky, Mia and Donna were sitting outside the usual room the group occupied, on a big sofa. They were chatting to the woman who ran the centre, who had a tiny puppy with her. The puppy (Shadow) was nestled next to Donna, being tickled as they talked. Everyone greeted me and asked me how my car (which had just been subject to some expensive repairs) was. I pulled up a chair and joined the conversation. From what I could make out, there was a discussion about group funding going on again. The ladies were talking about the need to set up a bank account for the group, but I soon understood that this was no easy task, due to the kind of paperwork that comes along with it. Similarly, the only bank left open in Oceanbridge is a Lloyds bank, and Becky told me they weren't 'too friendly at all' to setting up accounts for unofficial support groups like M.H.P.S.G. A suggestion was made to put money in at the post office and manage funds that way. I was shown a picture of one of the things that the funds might go towards:



24/11/2021, 12:46

Extra Large Sound Healing Tibetan Gong Handmade Gong Bell | Etsy UK

HimalCreations

224 sales | 4.3 ★★★★☆ (30 reviews)

Extra large sound healing tibetan gong- handmade gong bell - healing gong - meditation yoga - made from nepal

£397.56+

Low in stock

You save £70.15 (15%)

Local taxes included (where applicable)

Make 3 payments of £132.52. Klarna. No fees. Learn more

Diameter

Select a diameter

Add to basket

⌛

Selling fast! Only 7 left, and over 20 people have it in their baskets.

Highlights

Handmade

Materials: Seven metals, Silk, Rosewood

Description

Figure 8: The healing gong the group were hoping to purchase, if they got funding

I didn't really have any idea why the gong was such an important thing, aside from the brief mentions of spirituality and alternative medical practices I had heard at other meetings. I was told that it would be used as a basis for some of the group sessions, and would be a great thing for the group to own and use as a healing resource. It seemed like the urgent need to find a bank account was linked up to making the support group 'official' in the eyes of the many bureaucracies that governed the funding pot. With a bank account, helpful things, such as the healing gong, could be purchased and used by the group in their mission to help each other. I played with the puppy a bit while listening in to funding stuff and trying (and failing) to unpick all the acronyms I was hearing. No one else turned up to the group that day, so for the rest of the morning we sat around chatting and eating the left-over Greggs whenever we felt hungry. It was really nice to get to know the group members individually a bit more, and learn a little more about their lives.

Around halfway through the morning, the conversation turned to grief. Perhaps this was because only a few of us had chosen to attend that day and it was quite an intimate situation. Everyone spoke about people they had lost. It wasn't in a sad way, but more reflective. I learned that the group members had lost multiple family members to the sorts of diseases which are so very common in the North East: NCDs (non-communicable diseases) like blood clots, heart disease and cancers. The way we were talking made me feel as though Becky, Mia and Donna understood these diseases as mapping out part of their family's (and their own) futures. They spoke with no shock about these diagnoses, nor thought that there was anything strange about being diagnosed with, and dying from, one of these illnesses at a relatively young age.

From this, we got onto the subject of Covid. The new variant, Omicron, was gaining traction in the UK and we spoke about some of the concerns the women had about the vulnerability of both themselves and their families to serious infection. Becky told me that she thought this time round, it 'was a test' to see who would go back to being 'a sheep' and wearing masks. She expressed to me some worries she had about mandatory mask-wearing being implemented again. She told me that if that happened, 'we will be back in lockdown before we know it.' Mia had a slightly softer view, from her time spent working in a school, but agreed that she was sick and tired of it all and hoped we wouldn't end up locked up again. Donna, for a reason I didn't quite understand, connected the Covid-19 policy of the last few years up to Brexit, and more broadly to the fact the government were 'out to get' people like her. From here, the conversation shifted onto how the government was able to watch a lot of the things we do: through our phones, the conversations we had online and through recent Covid-19 control laws. The three women expressed worries that a lot of this surveillance, which had been seen so often during the pandemic, was aimed at people receiving benefits. They felt like there was an express aim to 'catch people out' and stop them receiving the state assistance they had obtained for their various diagnoses, if they were seen to be able to function to a certain level of ability.

The conversation changed track again. Becky told us that for the past week, all she had been able to taste and smell was smoke. My immediate thought was that it could be Covid, but Mia asked, interestedly and calmly, 'do you think it's someone trying to send you a message?'. I then understood that the conversation was about some of the clairvoyant abilities Becky had told me about on our first meeting. Becky went on to say it could well be. She knew three people who died in a house fire, and her dad had been a heavy smoker his whole life, right up until his death, so she thought it could be any one of them trying to talk to her. I looked at her as she sat next to me and contrasted my immediate thoughts of the meaning of this smoke smell to Mia's. At this point Becky got up, groaning, and the conversation stopped. She had been sitting still and chatting for too long, and had gotten stiff. It was a strange sight, her hopping about while we sat huddled together in our coats on the L-shaped sofa.

Donna got up to get a pasty from the stash of Greggs on the table next to us; Becky and I followed suit. Mine was cheese and onion - cold, but still good. Donna asked if anyone else with fibro had issues with their senses. She said she couldn't stand the tiniest of noises or strong smells- they made her very irritable. Becky and Mia chimed in with their own experiences and said that it could well be down to fibromyalgia, as they both experienced this too. These small, fragmented conversations were common to my experiences attending the support groups. Often, questions around symptoms would be tacked on to other conversations, asked as a, 'By the way, do you get this too?' comment to compare symptoms and experiences and ask for potential explanations. As these conversations occurred, participants took the opportunities to compare their experiences to others and participate in forms of biosociality which allowed them to verify their symptoms as looping into the 'fibromyalgia' diagnosis. This was even the case for those who were yet to obtain a formal diagnosis for the pain they were experiencing.

We talked, for a while, about the impact of Storm Arwen on the local community. I heard that a local care home had been left without power over the weekend. It had taken four days for an emergency generator to be set up and heat and power to be restored to a large group of very vulnerable people. Donna was angry about the fact that Durham Council had done absolutely nothing to help, and it had been the local community that had stepped *in with torches, hot food and blankets, to stop all the old people freezing to death. She asked the group why an emergency generator wasn't available to bring power back to the care home, after everything that people living in care homes had been through during the pandemic. To try and help, local people who had power had been filling up hot water bottles in their homes and carrying them over to the care home in an attempt to at least keep the residents warm. It was horrifying to hear. Some parts of the wealthier Durham city (only 20 minutes' drive away) had lost power during the storm, but had no issues with ongoing power cuts. I felt this story was emblematic of the stripping of social and economic support which has occurred in the local area over the last 15 years or so – now people, even in times of crisis, are willing to just deal with problems themselves rather than go through any of the official support networks that are supposed to exist. Reliance on the state now seems to exist mainly through the difficult links people have with their GPs, other forms of healthcare, and the DWP. There is very little existing infrastructure to deal with ongoing issues, or indeed emergencies like Storm Arwen.*

I thought about how we looked sitting there, and reflected on the morning as a series of images and sounds: us sitting around wrapped up in winter clothes, piles of donated pasties on the table next to us, Christmas decorations made by children decorating the walls, the sounds of babies laughing as they left a local 'mam and toddler' group, and a man dressed in full army uniform turning up to collect some vegetables from the foodbank before staggering off back home.

The importance of biosociality to people living under the diagnosis of chronic pain in the North East was always very clear to me. All my participants were recruited via their engagements with different support groups. Participation in these biosocial groups was inherently linked up with advocating for care and state resources. Importantly, this advocacy occurs in a very specific political context, and in a geographical location with deep histories of state neglect and ongoing problems with health inequalities. In this sense, I argue that biosociality in the North East was really always a form of biocitizenship; it was always oriented towards obtaining, or giving, some help or resource. This is clear in the above vignette – rather than waiting for assistance from the council, the local community worked together to provide the vulnerable residents of the care home with food and warmth.

The conversations I was party to at M.H.P.S.G. occurred in a specific space of biosociality – a support group for people who have chronic pain. Our conversations jumped around, but often circled back to themes of (questionably preventable) illness and suffering, state neglect and state control. It was clear to me while attending these group meetings that people understood the links between where they lived, the health conditions that affected them and their loved ones, and the healthcare they were able to access. Indeed, I often heard participants making jokes about how '*horrible*' Oceanbridge was. After I had explained to her what anthropology was, Donna told me that if I wanted to *'observe people'* I should just go down to the main road in Oceanbridge. By doing so, I'd learn all I needed to know about humanity (and *'not the good bits, mind'*). More seriously, the loss of loved ones via 'diseases of civilisation' (Pollard, 2008) was seen to be a normal and unremarkable thing. When Becky, Mia and Donna talked about their experiences of grief, they talked about the diseases that had affected their loved ones with an acceptance that this was not an uncommon thing to happen in Oceanbridge.

There was also a deep sense of exhaustion about the lack of resources that existed to help the myriad health problems affecting people in Oceanbridge and other parts of the North East. The mindset at the support groups I attended was one oriented around self-sufficiency. Decades of neglect at the hands of the state, and the underfunding of local councils, had led people to hold a kind of gritty determination to 'sort things out' and 'look after' themselves. The photo of the healing gong shown above represents this well. I found that much of the actual operation of the support group meetings was centred around the navigation of different bureaucracies, that might help to facilitate different forms of support and care. Questions about the effective use of the small amounts of resources the groups had access to were often at the forefront of discussion, before we moved on to arts and crafts. It is in these discussions of resource distribution that different forms of biocitizenship emerge – groups of 'damaged' people are making claims to different resources (even when these resources are often not provided by the state), in order to try and improve their health.

Furthermore, the wake of the Covid-19 lockdowns and the historic treatment of the recipients of state benefits had led to a deep suspicion of the state for many participants. The surveillance felt by Becky, Donna and Mia has a historical precedent, which can be broadly traced back to New Labour's welfare reform and societal attitudes towards benefits recipients during the late 1990s and 2000s (Fig. 9) (Hudson, 2005; Dorling, 2010; Hudson *et al.*, 2016). The explicit links made between Covid-19 restrictions and the surveillance of those who claim state benefits is emblematic of the feelings of distrust and neglect that exist in these communities more broadly. This is especially important when considering the Covid-19 laws which had governed the population's lives for the majority of the previous two years. These feelings of distrust are not unfounded – data from Scotland suggests that index of deprivation was correlated with risk of being convicted for breaking Covid-19 laws (McVie, 2022).

Figure 9: UK Government anti-benefits fraud poster campaign, 2006-2009 (Department for Work and Pensions, 2011)

In this context, claims made on the state for social welfare were often done so begrudgingly, and with the expectation that claims would be rejected as standard. This is why these groups worked so hard to provide support and care for themselves, rather than relying on the state. Worries about 'not acting sick enough' to be eligible for benefits dictated much of the behaviour I saw throughout my fieldwork. At another support group meeting, Becky guiltily showed me a video which she had saved on her phone. She was hula-hooping in it. She explained to me that some days she felt up to doing exercise of that intensity, but other days she could barely move. I could tell that she was worried about showing me the video in case I stopped believing in her pain. Memories of mistreatment by the state, both historic and recent, dictate attitudes and behaviours around claiming benefits. For Becky, Mia and Donna, there is the feeling that the claims they make to resources will be hard to obtain, no matter the circumstance. For them, engagements with the welfare state were contingent on performing the right kind of illness (which does not include being able to hula hoop on a 'good day'). With a diagnosis of fibromyalgia, performing this ideal illness was next to impossible; there are no diagnostic tests or biomarkers which can be used to 'prove' one's diagnosis. Instead, different methods had to be used to evidence the biological damage required to be eligible for benefits.

8.2 Traumatic landscapes and structural violence in North East England

8.2.1 Traumatic landscapes

Ivy's house, August 2021

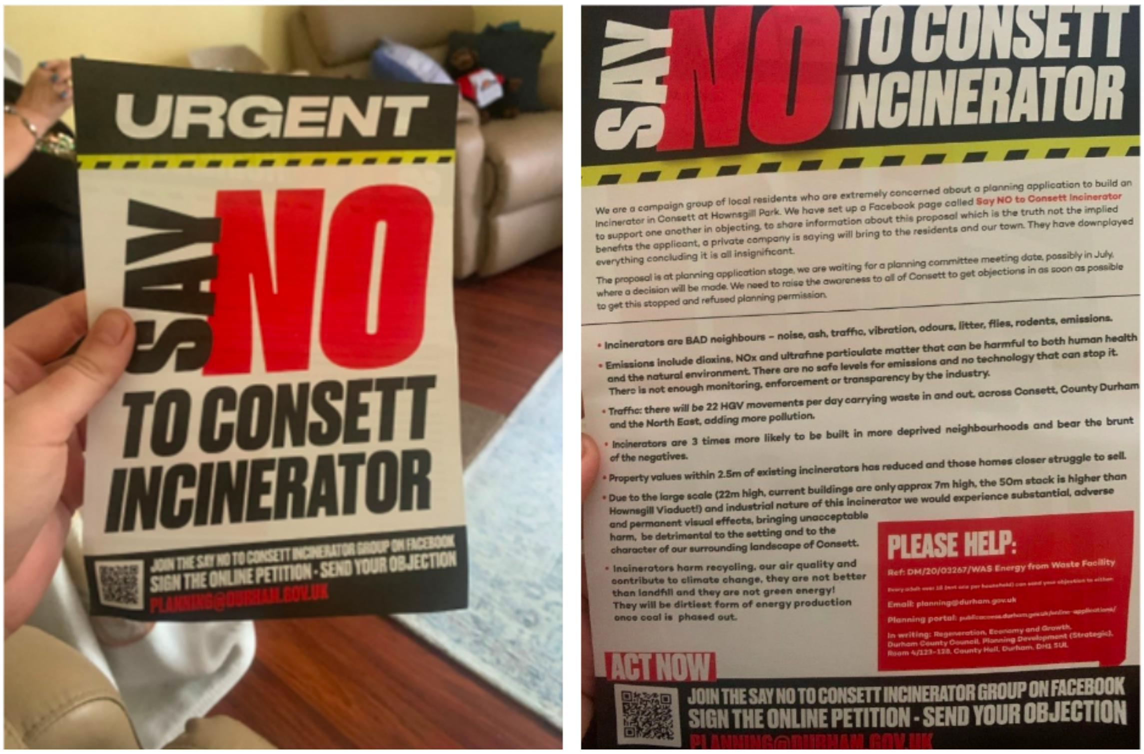
One afternoon in the summer of 2021, I was sitting with Ivy in her living room, drinking another one of her incredibly large coffees. We were talking about the changes to the local area she has witnessed over the 40 years she had lived in her village. She talked to me about her life growing up in Newcastle and how once she had moved out to the countryside, she had felt she could never go back to city life. As we spoke, she asked me if I had heard about what was happening in Consett, the nearest large town to her house. She told me that a company wanted to build a huge incinerator, and that this was being faced with a lot of opposition by local communities who were worried about the impact further pollution would have on their health. When I said I hadn't heard about this at all, she handed me a flier with more information (Fig.10).

The flier provided information about local protests going on regarding the planned building of the incinerator. Ivy gave me some more background to why this was such an issue in Consett: the town was historically a steel producing hub, and has faced difficulties with unemployment since the closure of the steelworks in the 1980s (Foote Wood, 2009). Improvement in unemployment levels is given as one reason for the building of the incinerator, with claims made by the company that the incinerator would bring jobs to the town and provide opportunities where there were few.

However, Ivy and other local residents had different concerns. Worries about damage (both to the environment and to residents' health) which could be caused by the building of an incinerator are central to the opposing argument put forward on the flier. It asserts that there are 'no safe levels for emissions' and observes that the incinerator industry is fundamentally unregulated, indicating that the building of the incinerator would put the health of local populations at risk. Similarly, the flier notes an observation that incinerators are more likely to be built in deprived areas, such as Consett, and that there are strong links between deprivation and poor health which may be exacerbated by the release of pollutants into the air.

The argument made here demonstrates the awareness communities have about both the health problems that living in a damaged landscape can cause, and that this damage is an unfairly distributed, ongoing issue. In other words, there is an acute consciousness of the specific geographical, social and environmental histories that have made Consett subject to the kind of debates seen above. All of this information must be contextualised with the knowledge that Consett is situated within the culture of the ex-industrial communities which populate

County Durham. Ideas about environmental pollution and harm in the North East have backstories which date back generations. Most of my older participants knew people who had worked in the coal or steel industries, and many aligned the poor health of the older populations in the North East directly with these industries.



URGENT

SAY NO TO CONSETT INCINERATOR

JOIN THE SAY NO TO CONSETT INCINERATOR GROUP ON FACEBOOK
SIGN THE ONLINE PETITION - SEND YOUR OBJECTION
PLANNING@DURHAM.GOV.UK

SAY NO TO CONSETT INCINERATOR

We are a campaign group of local residents who are extremely concerned about a planning application to build an Incinerator in Consett at Hownsgill Park. We have set up a Facebook page called Say NO to Consett Incinerator to support one another in objecting, to share information about this proposal which is the truth not the implied benefits the applicant, a private company is saying will bring to the residents and our town. They have downplayed everything concluding it is all insignificant.

The proposal is at planning application stage, we are waiting for a planning committee meeting date, possibly in July, where a decision will be made. We need to raise the awareness to all of Consett to get objections in as soon as possible to get this stopped and refused planning permission.

- Incinerators are BAD neighbours – noise, ash, traffic, vibration, odours, litter, flies, rodents, emissions.
- Emissions include dioxins, NOx and ultrafine particulate matter that can be harmful to both human health and the natural environment. There are no safe levels for emissions and no technology that can stop it. There is not enough monitoring, enforcement or transparency by the industry.
- Traffic: there will be 22 HGV movements per day carrying waste in and out, across Consett, County Durham and the North East, adding more pollution.
- Incinerators are 3 times more likely to be built in more deprived neighbourhoods and bear the brunt of the negatives.
- Property values within 2.5m of existing incinerators has reduced and those homes closer struggle to sell.
- Due to the large scale (22m high, current buildings are only approx 7m high, the 50m stack is higher than Hownsgill Viaduct!) and industrial nature of this incinerator we would experience substantial, adverse and permanent visual effects, bringing unacceptable harm, be detrimental to the setting and to the character of our surrounding landscape of Consett.
- Incinerators harm recycling, our air quality and contribute to climate change, they are not better than landfill and they are not green energy! They will be dirtiest form of energy production once coal is phased out.

PLEASE HELP:

Ref: DM/20/03267/WAS Energy from Waste Facility

Every adult over 18 (not one per household) can send your objection to either

Email: planning@durham.gov.uk

Planning portal: publicaccess.durham.gov.uk/online-applications/

In writing: Regeneration, Economy and Growth, Durham County Council, Planning Development (Strategic), Room 4/123-128, County Hall, Durham, DH1 5UL

ACT NOW

JOIN THE SAY NO TO CONSETT INCINERATOR GROUP ON FACEBOOK
SIGN THE ONLINE PETITION - SEND YOUR OBJECTION
PLANNING@DURHAM.GOV.UK

Figure 10: Flier outlining the rationale for the Consett incinerator protests

In this chapter, I argue that the post-industrial context of the North East can be considered as an example of a 'traumatic landscape' (Proudfoot, 2019). This is especially useful when thinking in terms of the documented inequalities in chronic pain prevalence, opioid use and deprivation which were the original premise of this PhD (Mordecai *et al.*, 2018; Todd *et al.*, 2018; Curtis *et al.*, 2019). The term 'traumatic landscapes' was developed by Proudfoot (2019) in his analysis of addiction in Chicago. It describes how individual illnesses can be traced back to the broader socio-political forces that impact specific places. Proudfoot presents the 'traumatic landscape' as a counter to the more famous 'therapeutic landscapes' – places which promote, or are generative, of healing – as described by Gesler, (1992). These 'therapeutic landscapes' are well documented in health geography and are used to explore how the relationships between health and place are relational, and always socio-political (Bell *et al.*, 2018).

Proudfoot (2019) uses these principles to argue that the antonym of the therapeutic landscape is not simply an 'unhealthy' landscape, but rather what he understands as the 'traumatic landscape'. In fact, 'place' can have a directly negative effect on health. To illustrate this, he uses two case studies from fieldwork undertaken on drug use in Chicago. He argues that to fully understand the dynamics of addiction, we need to first understand the contexts in which these addictions occur, such as areas where extreme poverty and/or violence is rife. Using case studies, Proudfoot (2019) highlights that there are specific dynamics which exist between 'traumatic places' and the problematic use of drugs. In this chapter, I argue that the relationships between health and place in the North East serve to generate the forms of biocitizenship I have described above.

The traumatic landscapes of the North East can be demonstrated well through the example of the proposed Consett incinerator. As discussed in the introduction to this thesis, the North East has been subject to specific forms of post-industrial decline. This decline has had a documented impact on inequality and by extension the overall health of local populations (Dorling, 2012; Marmot, 2020a, 2020b). The opposition to the building of the Consett incinerator shows the explicit links between industry, health and place that exist in the North East. Those protesting against the incinerator have clear knowledge about the potential that the building of this structure could have to damage health. Furthermore, the flier itself highlights the unfairness of the incinerator being built in a place that had already been subject to the negative impacts of industry for many years, stating that, 'incinerators are three times more likely to be built in deprived neighbourhoods and bear the brunt of the negatives'. When she showed me the flier, Ivy explained that the incinerator was planned to be built near to where her grandchildren worked, and she worried about the impact it might have on their health in the future.

Through the example of the incinerator, it is possible to see the links between health and place as they are felt by my participants. Ivy showed me the flier for a reason – it was to illustrate the worries she had about the incinerator's impact on her own, and her family's, health. The incinerator itself, if built[10], would serve as a representational marker of the ongoing industrial history of the North East on the landscape. This landscape itself is a traumatic one. Throughout my fieldwork, I saw that participants felt that where they lived, and the lack of resources the area had, was linked with their poor health. While talking to people, I heard that the sorts of health resources helpful for those living under a diagnosis of chronic pain in the North East had mostly ceased to exist over the last few years. This was especially notable in the context of Covid-19. Specifically, the closure of local specialist hydrotherapy pools was mentioned to me on multiple occasions, with only one pool remaining open for the whole of the North East. The closure of these pools was lamented as the loss of one of the final places people with chronic pain could go to seek non-pharmacological pain relief. This left people feeling as though their treatment options were very much limited to what medications they could get from their GP, and what support systems they could create for themselves.

8.2.2 Structural violence

Here, I argue that the traumatic landscapes described above are an example of how structural violence can become embedded in different landscapes. By thinking about the North East as a traumatic landscape, I argue it is possible to see the 'social machinery of oppression' (Farmer, 2004a: 307) more clearly and consider further how it takes shape and form in different places. When theorising about structural violence, it is important to consider where it is situated. As outlined in the introduction, health inequalities data has repeatedly demonstrated issues that are very specific to North East England, and so it is crucial to think further about the links that exist between place and health to understand this inequality further (Bambra and Garthwaite, 2015; Corris *et al.*, 2020; Marmot, 2020).

Thinking about both of the ethnographic examples presented in this chapter so far can help to show how various threads of decline knit together to form the contemporary situation. Lack of investment, unstable and unreliable infrastructure, embedded inequalities, and mistrust of the state all cumulate to produce a traumatic landscape. Following Proudfoot (2019), I argue the traumatic landscapes of the North East may serve to help generate the

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[10] At the time of writing, this is still undecided.

chronic health conditions which affect significant numbers of people in the local area. For my participants, there was a loss in faith that any larger structures were 'there' to help them. The example of the M.H.P.S.G. meeting, and the proposed building of the Consett incinerator, both invoke feelings of being 'left behind'. Why was the infrastructure on the coast not able to withstand an unexpected, but not unprecedented, storm? Why did the local community have to step in to ensure the safety of the people living in the care home? Why was an incinerator proposed to be built in an area historically negatively impacted by heavy industry?

Here, I want to be explicit about the links I have seen between the process of biocitizenship in the North East, and the traumatic landscapes within which this biocitizenship exists. Biosocial groups developed around the different diagnoses my participants lived under. These groups existed in areas of very low resource, where there are historical feelings of social neglect. The direct aims of these groups were therefore to seek and obtain different forms of care. Ideas of community support were essential to how my participants understood the environments they lived in, but this came alongside the knowledge that in times of crisis (such as storm Arwen) this community support would be nearly all there was. There was always an attitude of needing to 'make things work' and 'finding ways to manage' in an environment that made being healthy difficult.

8.3 Access to state benefits

Post-industrial North East England and post-disaster Chernobyl are two examples of traumatic landscapes within which reside citizens who need to prove damaged biology in order to obtain state resources. In Chernobyl, this biological damage could be evidenced through specific exposure to specific amounts of radiation, as was dictated by the Ukrainian government (Petryna, 2002: 118). In the North East, this damage manifests through the physical health effects that the long-term consequences of heavy industry can have on individual bodies (Pless-Mulloli *et al.*, 1998). However, it also manifests through the psychic and social effects that emerge when a person lives in a traumatic landscape, where resources are increasingly scarce. In both the case of post-disaster Chernobyl and post-industrial North East England, individuals need to participate in biological citizenship to ensure access to the welfare state. In the final section of this chapter, I turn back to the definition of biocitizenship offered by Petryna (2002), and consider further its application to my participants' lives:

> 'One can describe biological citizenship as a massive demand for but selective access to a form of social welfare based on medical, scientific, and legal criteria that both acknowledge biological injury and compensate for it. Such demands are also being formulated in the context of fundamental losses - loss of primary securities such as employment and state protections against inflation and a general corrosion of legal-political categories.'
> (Petryna, 2002: 6)

In what follows, I explore the precarity experienced by my participants as they tried to navigate the British welfare state while living under a diagnosis of chronic pain. As mentioned in Chapters Four and Five, living under a diagnosis of chronic illness often entails living at the 'borderlands' between sickness and wellness. These illnesses are often those you 'have to fight to get' (Dumit, 2006). This fight becomes especially important when individuals are required to make claims based on specific diagnoses and evidenced biological damage to their bodies, in order to obtain state sickness benefits.

The commonalities between Petryna's ethnography and my participants' experiences lie in the ways that engagements with the state, in damaged 'traumatic landscapes', need to have a biological basis of some form to be considered legitimate. For Petryna's interlocutors, this was done through the production of medical documents and through participating in medical testing which could be used to record specific levels of previous exposure to damaging radiation. For my participants, 'proving' their illnesses in order to be believed could not be done in the same way. In fact, often the social welfare system was set up in such a way that it was impossible for participants to adequately prove the impact of their disabilities on daily life. Instead, biocitizenship was obtained through engagements with support groups, and ways to prove (or not) appropriate damage to their bodies were negotiated as they engaged with these groups. By participating in these support groups, participants learned ways to live under diagnosis in the traumatic landscapes of the North East. By doing so, they were able to engage with the welfare state and learn ways to 'prove' damage to their bodies in the 'right' way.

8.3.1 Cultural ideas around work and sickness

Ideas about work, sickness, benefits and the impact of successive austerity policies were infused throughout my fieldwork experiences. The areas I worked in were home to working class, traditionally Labour-voting ex-mining communities[11], and this political orientation left marks on the people I worked with. When I first met George, at Chronic Pain care, he asked me *'are you a Tory if you're a Durham student then?'* within the first few minutes of meeting me. When I said I wasn't a Tory, he expressed that it was, *'...alright to talk to me then'* and that I was welcome at the group.

Work, as a concept and a marker of social identity, was equally as important to my participants as their political identity. It became clear to me, as I spoke to people throughout fieldwork, that 'not working' was a stigmatised state of being, no matter how sick a person was. Often, there was the perception that people up in the North East 'worked hard' and would inevitably get sick at some point during their lives, requiring some state support in return for their years of hard work. This inevitability of 'becoming sick' is reflected in wider epidemiological data. Public Health England statistics placed 'healthy life expectancy' (years spent in good health) in the North East at 59.4 years for men and 59.0 years for women, with lower back pain as the leading cause of healthy years 'lost' (Office for Health Improvement and Disparities, 2021).

As Thelma texted me one afternoon:

> something worth pointing out obvious as it seems. Working class literally live hand to mouth, no work = no money for food/heating. it's frowned upon socially not to work at all also, there really is stigma. no one wants time off work long term 'n' it means chronic pain needs to be managed to a level of functionality.

This idea of functionality is important, and something I saw repeatedly. Often, people would describe to me the various ways they tried to work around their disabilities to stay in employment, even if this meant compromising their health. In the introduction to this thesis, I provided a brief overview of the history of the British welfare state. Here, I look to how people actually obtained these benefits in practice. The majority of my participants had sought, or were in the process of seeking, PIP (Personal Independence Payment). Many of them were also on Universal Credit or ESA (Employment Sickness Allowance), but some chose only to try and

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[11] Although this has started to change in recent years

obtain PIP to allow them to still work without restrictions (while in receipt of ESA, claimants are limited to 16 hours per week paid work).

Seeking access to PIP and other benefits forms a substantial part of living under diagnosis, as access to these resources provides individuals with further financial stability, and access to extra funds to make their lives more liveable. Importantly, and as noted by Thelma above, ideas about the need to work were still very much ingrained in the psyche of my participants. The stigma that surrounds not working was ever present throughout my field encounters – if a person was on full sickness benefits, I would often be given a very biological explanation for why this was the case. People would often reference both the engagements they had had with the welfare state, and the biological damage which had led to the attainment of these sickness benefits. Even for participants who were of retirement age, the kind of job they had done in the past would still be offered to me as evidence of how they had been 'useful' before they became sick, and a reason for their retirement would be given.

Here, it is possible to see how people delicately navigated being 'sick enough' to eligible for a benefit like PIP, without being 'too sick to work' full stop. My participants had to find ways to prove that they were damaged enough to obtain PIP, without being so sick they could not work at all. Obtaining PIP but still being seen as 'well enough to work' was a delicate balancing act. It involved demonstrating to the relevant authorities that pain could be managed functionally, while still requiring some assistance from the state.

8.3.2 Navigating the benefits system while living under diagnosis

PIP awards are decided via an assessment process. Access to this benefit did not come easily. I heard many stories of rejection, as well as stories of people being faced with disbelief when being assessed for PIP. In response to this disbelief, ways of navigating and circumventing the system to evidence the 'right' forms of biological injury were developed, much in the way Petryna (2002) details in Life Exposed. Ella, whose diagnosis history was told in depth in Chapter Four, spoke to me on multiple occasions about her experiences with the benefits system. As described in Chapter Seven, Ella had boxes and boxes of tramadol tablets stashed in her bathroom cabinet. We met up for a walk, in late August 2021, and spoke about this further:

Excerpt from fieldnotes, walk with Ella 25.8.21

We spoke about the PIP and ESA process. Ella got her phone out and told me that she had taken pictures of her successful PIP application, so she could remember what she had put for future applications. She read out some of the questions she had been asked, and how she had answered them. The application form asked: 'How do you use the kitchen?' and she had responded: 'My partner cooks for me or I have to rest, I can't use the microwave without sitting down'. There were questions about washing, socialising, walking, and importantly, medication. She read me answers detailing the tiny ways her conditions impact on her day to day life. For this application, she had been awarded PIP. I asked why she didn't apply for ESA and she told me that the PIP application was enough for her. I also asked if she was still filling her tramadol prescriptions without taking them regularly, and she nodded, acknowledging that it was perhaps deceptive but the amount of the PIP form which focuses on medications is huge, so she felt like she needed to have something to put down on there about what she was prescribed for her conditions.

Ella and I spoke at length about the guilt she feels about claiming PIP because she still works, and still wants to work to avoid the stigma of not doing so. But for Ella, her health is so unpredictable that she needs PIP to maintain her freedom. In the same breath, she also told me how she feels like you must be so incredibly sick to 'deserve' PIP. 'The system is rigged,' she told me, flatly. 'Do none of these politicians know it could be them?'

Implicit knowledge about how to navigate the benefits system was often communicated between people. When Ella took a photo of her successful application, it was to record the 'correct way' to answer the questions in order to obtain the maximum amount of points on the assessment. At support groups, people would often talk about the assessment process in the way Ella and I did above, outlining the contradictions that occurred during the claims process. By doing so, looping effects (Hacking, 1995) emerge again. The 'right' way to describe symptoms vs the 'reality' of these symptoms is navigated by individuals and groups of people. By communicating *how* the benefits system is navigated, collective claims for state support (or, self-ascriptive kinds) are made. Through attending support groups and participating in the official bureaucratic procedures I never managed to understand, people learned how to perform the processes of legitimisation required to obtain benefits and other forms of 'official' state support for their illnesses.

8.3.3 Evidencing biological injury

Navigating PIP applications made many participants feel both guilty and angry at the same time. When the word 'PIP' was mentioned at support groups, it was met with tuts, eye rolls and angry sighs. From there, people would often detail the latest frustration they were having with their claims, and would be met with words of empathy about the difficulties of navigating a system not made for people who live with chronic health conditions.

My participants knew of the ways they could appear more acceptably 'biologically damaged', and more easily gain access to social welfare. In Ella's case, continuing to pick up her tramadol prescriptions without taking them allowed her to evidence to her GP (and as a consequence to the state) that there was some kind of biological injury deep in her body, which could be aided through the ingestion of strong painkillers. Knowledge about the benefits system is often centred around allowing people to access state benefits while still living full lives. People have to find ways to demonstrate 'biological damage' while also contending with the realities of their illnesses, which can vary in symptoms from day-to-day. For example, by filling her prescriptions, but only taking them when needed, Ella demonstrated much learned, often justifiably cynical knowledge, about how this system works.

Part of the reason for Ella's continuous filling of her prescriptions (despite taking tramadol infrequently, for acute pain flare ups) is so that when she applies for PIP her medical records show that she is taking strong painkillers for her fibromyalgia. This will evidence further that her diagnosis is 'real', or, as Petryna (2002) would understand it, that there is biological damage to her body which is alleviated by painkillers. Rather than having to demonstrate certain levels of damage from radiation, my participants had to find other ways to show their bodies were 'damaged enough' to get the support they needed.

Participants often felt that any small positive thing they had in their life would count against them in a PIP claim, as it would show they were physically 'healthy' and therefore not damaged 'enough' to be eligible for the benefit. As I described earlier, when Becky showed me the secret video of her hula- hooping, she worried that a record of her doing exercise might be used against her during her benefits claim. This idea of evidencing the 'right' kind of illness was something that participants talked about a lot. Here, I use an excerpt from some fieldnotes from a conversation I had with Clare in summer 2021. Clare's experiences demonstrate how people learn to participate in the right form of biocitizenship, in order to demonstrate the 'right' kind of damage to their bodies using appropriate evidence.

Dog Café with Clare, excerpt from fieldnotes, July 2021

I was in the dog cafe with Clare again, watching people fuss over Benny. As we watched the dog eat his sausage, she added, as an afterthought to the conversation we were having (about her current fibromyalgia symptoms), 'that's another thing - you get judged for having a dog when you apply for PIP.' As we sat together at the table, she went on to tell me about the different kinds of questions she had been asked in her assessment, and how frustrating it was to try and answer these questions for an illness which was so variable and had no clear physical cause. 'How am I meant to describe what I can do in a day, when it changes day to day?' she asked me. I couldn't answer her.

These feelings of suspicion, surveillance and not being believed by the authorities were extremely pervasive. Every time I spoke to Julie, one thing she wanted to talk to me about was her application for PIP. Throughout the time we knew each other, she was working full time as a carer – a job she found physically and mentally exhausting. She expressed the frustration she felt when she was told by her doctors to keep moving and exercising, and also trying to work. She felt that if she worked full time and exercised regularly, then it would be used as evidence against her in any claim she made for benefits, despite this being her recommended treatment plan for pain. If she did what her doctors told her to do, she would not be seen as ill enough to get PIP. Without PIP, she had to work more, and felt more unwell.

Coffee with Julie, excerpt from fieldnotes, May 2021

We switched back to taking about PIP a bit more – she has logged a change in circumstance as she's been feeling so ill recently and wants to work less hours, if possible. But she strongly believes the fact she works at all is held against her. She is still waiting for her pain clinic referral, as the things she has been given for pain management previously, like a TENS machine, aren't working any more.

We talked about how weird fibromyalgia is, with the sun beating down on us. It was surprisingly private - the noise from the road masked the noise from the tables around us. She showed me the strange, circular bruises which appear on her body when she has a fibromyalgia flare up, and showed me some photos from the skin graft she had 8 years ago. They were gruesome, and I flinched when seeing them. She told me she got diagnosed with fibro and, 'that was that.' After the diagnosis, accessing services had been like, '...hitting a brick wall,' even though at the moment even sleeping is a tiring experience for her.

We went back to PIP again and she wondered why she had bothered paying into the system for so long when she couldn't access the support net which is meant to be there to catch people. She expressed frustration about how hard it is to work when all she wants to do is sleep – she often has to choose between taking her medication and working. Her medication makes her so sleepy that she couldn't do her job as a carer properly if she took it.

Although, she then added that the medication didn't even seem to work anymore, so taking it was pointless anyway.

I could sense she was getting tired, so I pushed to ask one more question before we parted ways. I asked what she thought she actually needed, support wise. She responded: 'What do I need? To not be in pain for a day, an hour, even 10 minutes… to be treated with respect and dignity… and to not be thought I'm lying.' She then went on to tell me a story about being in A&E with endometriosis pain, and hearing a nurse telling another nurse that the reason for there being so many pain patents in on that day was that it was 'near PIP renewal time.' We looked at each other with annoyance after she told this story, because there is no such thing as 'PIP renewal time' – the applications are done on a rolling basis. She told me how, after hearing that, she stared at that nurse with complete distaste for the rest of the time she was in A&E. In the end, she was offered nothing stronger than co-codamol to manage the pain she was in.

Both Clare's and Julie's examples show that, to access state benefits, certain levels of biological injury or impairment need to be demonstrated. The knowledge of how to do this is learned and communicated between people and groups. Even as we were talking, Julie was keen to show me physical evidence of the pain she was in, through showing me photos and parts of her body that were bruised, and the pictures she had taken after her skin graft several years ago. Demonstrating this biological damage is difficult for many reasons. As I have described, accessing a diagnosis for many conditions that cause chronic pain can be a long and arduous process which occurs via 'exclusion' rather than positive tests. Similarly, the symptoms of chronic pain can vary day to day. As Clare noted, there is no way to succinctly predict what a person would be able to do on any given day, so to engage with the benefits assessment process meant that participants had to learn to answer the questions the 'right' way.

For Julie, access to PIP was a constant worry, causing her a lot of distress and impacting significantly on her mental health and sense of self-worth. The stigma Julie had faced when seeking care for her pain often linked back to a deeply held perception that those on state benefits are 'faking it'. 'Not being believed' has been discussed in this thesis, but this is especially important here when we consider the complex links between individuals and the state that are forged through the processes of biocitizenship. For those who claimed benefits, there was an inherent knowledge, often discussed in support groups, that to be believed was to demonstrate that there was 'something wrong' with their bodies and the way they functioned.

8.4 Conclusion

In this chapter, I have brought together ideas about biocitizenship, 'traumatic landscapes' and the British welfare state. By drawing together three key points, I have attempted to emphasise the importance of place when thinking about life under diagnosis. These three key points are as follows. Firstly, support group meetings between individuals living under the diagnosis of chronic pain were always oriented towards accessing resources and support, whether that came from within the group itself, or from the state. In this sense, these groups always involved participation in forms of biocitizenship. Secondly, I have argued that this biocitizenship occurs specifically in the traumatic landscapes (Proudfoot, 2019) of North East England. Where health is poor and resources are scarce, people have to find new ways to access help and support for their diagnoses. Finally, this chapter has discussed how my participants learned specific ways to navigate the benefits system, in order to participate in biocitizenship and prove biological damage to their bodies. This allowed them to find ways to access state support for their illnesses.

The forms of biocitizenship mobilised by my participants had one broad aim: to access resources and care in whatever form they were available. The need for self-sufficiency, the lack of state support for poor health and the impact of structural violence on the North East were ever-present in conversations at support groups. The meetings of these groups were hubs of activity where knowledge about how to obtain scarce resources were traded, and mechanisms of care were enacted.

For the women I worked with during my fieldwork, living in traumatic landscapes can be aptly described as being subject to Tudor Hart's (1971) inverse care law – areas of high need and low resource. As a result, when people became chronically ill, they needed to find the best, easiest and quickest ways to access state support. Cultural ideas around work and employment, alongside a welfare state which is suspicious of those it is meant to help, meant that sickness had to be demonstrated in concrete, biological ways.

More often than not, state support was contingent on the continued demonstration of biological damage to bodies. This damage could not be causally linked to the traumatic landscapes within which these women resided, such as is the case in Petryna's (2002) ethnography. Instead, it had to be proven through individual actions (taking certain medications, not doing certain activities, performing illness in certain ways) and the evidencing of biological damage to an individual, rather than collective, bodies. In this sense, biocitizenship heavily shaped everyday life under diagnosis; it influenced what happened at support groups, and it changed the narratives that existed around people's understanding and articulation of their own biology in relation to their pain.

SECTION THREE: THE FUTURE (?)

9 Chapter Nine: Living through Crip Time and the Subjunctivity of Chronic Illness

This chapter looks to the various imagined future(s) which necessarily constitute living under a diagnosis of chronic pain. As I contemplate what the future looks like to those living under diagnosis, I consider the role of chance, and the importance of hope and community, in creating lives worth living in the face of structural violence. To do this, I first turn back to the day which opened this thesis – the day I spent with Thelma and her two girls at Beamish in August 2021. This vignette demonstrates the small moments of joy that occur when people who live with chronic pain ignore, or suspend, the potential dictates of the future placed upon them by their diagnosis:

Going on the carousel, August 2022

Halfway through the day at Beamish, we headed to the fairground. It was starting to get hot and I was glad I'd covered my arms in sun cream before leaving my car. We were moving downhill, Thelma was freewheeling with Georgina on her knee, and everyone was giggling. Georgina hopped down from Thelma's knee and ran off with her sister. They ran faster and faster as the fairground loomed in the distance. Thelma shouted for them to slow down but they didn't listen, so she went after them, putting her chair at full speed. It was going fast, and I could see that going over the bumps in the path caused her pain.

We finally got to the fairground after catching up with the girls. It was full of kids, and circus music drifted around us. There was a kiosk selling food and drink. Thelma stopped to get herself a bottle of water and a carton of apple juice for each of the girls. The kiosk was clearly not made with wheelchair users in mind — Thelma's eyes barely grazed the hatch, and the attendant couldn't see her for a while. When paying, the woman serving had to stretch the card machine out and over, at full arm's length, so that Thelma could tap her card on it.

Next on our list was tokens for the rides. We queued up again, Thelma having to ask several people to stop standing in the way so she could get to where the queue was. At the front of the queue Bethany darted in front of Thelma, and started asking the man serving us for tokens, grabbing everything in sight. He didn't seem to have much patience for her at all, and grabbed her hand to stop her touching the coins. Thelma immediately asked Bethany to sanitise her hands, citing worries about Covid as the reason.

Finally, we reached the highlight of any visit to the fairground, and all went on the big carousel. It was here that I began to feel really annoyed at the cumulative ignorance Thelma had faced throughout the day. The fairground was busy and people were treating Thelma like she was invisible, pushing in front of her, or worse, standing directly in the way of her wheelchair, only moving when I went to the front of the group and manoeuvred us through. While queuing for the ride we got several dirty looks.

We got to front of the queue and much to the bemusement of the man working there, Thelma decisively left her wheelchair by the side of the carousel and used her crutches to lift herself up and onto the ride, determined to enjoy this moment with me and her girls. We all sat in a sleigh, which had enough seats to house us all together, *laughing and looking at the colours and sounds. Thelma warned us not to look in the mirrors for fear that we might get dizzy.*

As we rode, spinning round and round, Thelma told me, in between the girls' shrieks of laughter, that this was 'the reality of being a mother'. She knew that getting on this ride would cause her pain in the long run, but she chose to do it anyway to create happy memories with her girls that would last forever. Hoisting herself up onto the carousel was worth it – it meant she got to experience something joyful before the inevitable pain. As the ride slowed down, Thelma stiffened slightly – she thought her wheelchair had been taken and asked me to stand up to confirm that I could still see it. When it came back into her view, she relaxed. The ride finally stopped and Thelma slowly brought herself down to the ground, while Bethany held the crutches ready to give back to her mam. I know that I will always remember that afternoon.

The above vignette speaks to many of the themes present in this thesis; Thelma's experiences at the fairground paint a specific picture of disabled motherhood and the discrimination it brings with it. However, in this chapter I will focus on how living life under diagnosis impacts choices about the future. These choices are imagined around a potential version of the future which, for the women who took part in my research, is unpredictable or uncertain while being simultaneously immovable and pre-ordained.

Living under a diagnosis chronic pain is dictated through maxims such as *'if I do this today, I will hurt tomorrow'*. When Thelma chose to drag herself out of her wheelchair and onto the carousel, it was with the explicit knowledge that she would 'pay for it' with increased pain in the future. But, in Thelma's eyes, the potential for pain in the future was outweighed by the chance to 'make memories' and spend time with her loved ones. Just for a second having the option of living without anticipating what might happen tomorrow made the pain 'worth it'. Even so, while we were on the ride, she was constantly on the lookout for potential challenges that *might* make her life harder. Her worries about losing her wheelchair – her main form of mobility – were always present in her consciousness.

This chapter discusses participants' considerations for what the future has in store for them, or perhaps more precisely the potentiality or *subjunctivity* (Whyte, 2002) that comes alongside this anticipation of the future. In my literature review, I discussed temporality from the perspective of both medical anthropology and disability studies. The first section of this chapter contrasts knowledge drawn from this literature with the medical guidance given by the NHS for people living under a diagnosis of chronic pain. This guidance emphasises the importance of 'pacing' to effectively manage pain. However, there are often tensions between this guidance and the realities of life under diagnosis.

To explore this further, I consider the trade-offs that are made in everyday life by my participants; the choices they make to allow them to stay 'well' in the future. These trade-offs between the present and the future can be broadly aligned with research focused on the future-oriented management of different chronic illnesses; 'positive living' and HIV/AIDs (Benton, Sangaramoorthy and Kalofonos, 2017) and healthy eating and obesity related diseases (Hardin, 2021). They can also be aligned with work generated at the intersection of disability studies and queer theory (McRuer, 2006) on the concept of crip time (Kafer, 2013). While the trade-offs discussed in the first section of the chapter are often used to preserve energy and ensure that pain remains at manageable levels in the future, sometimes, as is demonstrated in the opening vignette to this chapter, the present takes precedence.

The second section of this chapter considers *why* these breaks in 'positive' and 'health promoting' behaviours occur. Sometimes, the future is navigated in complex and contradictory ways, which might seem counterintuitive to those not living under diagnosis. For those navigating an uncertain, or subjunctive future with regards to their health, 'the intentions, hopes and doubts of people looking toward an immediate future' (Whyte, 2002) take precedence. The question I aim to answer in this second section is: *why would someone perform an action that might cause them pain in the future*?

By looking to the uncertainty and complexity that shapes life under diagnosis, I consider how love, joy, and support is formed because of (and often despite) the pressures of the future. Indeed, in the context of chronic pain and disability, looking to the future may allow us to 'see, and do, the present differently' Kafer (2013:28). Within the communities and families I worked with during my fieldwork, anticipating the future while chronically ill was often made complicated by the search for moments of joy. While often 'healthy' choices were made, sometimes choices that were 'unhealthy' were more important because they provided moments of joy.

This chapter works towards a more utopian view of disability and chronic pain. I explore why people might make decisions to do activities that are 'not good' for their pain, to build more joyful lives for themselves and their loved ones. Pandian (2019) describes how anthropology can open up the horizons of new possible humanities, and remake the worlds we live in for the better. Undoubtedly, most of the topics described in this thesis are united by a common theme of misery; traumatic life experiences, state violence, long illness histories, iatrogenic harm. Despite this, in this final chapter, I want to consider what joy looks like to my participants, in turn emphasising the disability futures we could imagine when thinking about *how* people actually live under the diagnosis of chronic pain.

During my time in the field I saw a lot of pain. However, alongside this was a lot of joy which needs to be represented in this thesis too. Often, this joy had a subversive, defiant air which challenges the ideas many people may have about what life as a disabled person 'should' look like. While living under a diagnosis of chronic pain means living with an uncertain future, sometimes it also means seizing the present and finding community, joy and humour in unexpected places.

9.1 'Worth it' pain, 'Pacing', and the consequences of 'overdoing it'

9.1.1 'Worth' It Pain

A trip to Oceanbridge, Summer 2021

Clare and I had planned to visit the seaside. We had made these plans a few weeks in advance, as Clare had mentioned that she hadn't been out of Durham city in ages. On the day we were supposed to go, I had woken up at 3am with a funny feeling that she was going to cancel. Sure enough, when I looked at my phone later that morning I had received the following text:

> ‘not going to manage the beach day. Feelings of overwhelming anxiety have hit. Which have caused pain around my shoulders, arms and back. :(I hate my physical life’

I felt horrible for her. She had told me multiple times how much she was looking forward to seeing the sea and watching her dog play on the beach. I reassured her that I completely understood and that we could plan another beach day when she was feeling well enough. I offered to drive over to her house so we could have a cup of tea together, so that she wouldn’t be on her own all day feeling terrible. She agreed and I set off an hour later.

When I arrived, Clare opened the door with a look of determination on her face. ‘I think we should go to Oceanbridge’ she told me. She explained that she didn’t want her pain and anxiety to get the better of her this time. I asked if she was sure about going and she said enthusiastically ‘YES’. She offered to drive as she had a prescription to pick up, so we quickly set off on our road trip.

When we arrived in Oceanbridge we parked up and went to get fish and chips, which we ate overlooking the sea. After we had finished, Clare popped to the bin while I held Benny’s lead. She left holding a towering pile of our fish and chip wrappers, joking that she looked greedy.

Before heading home, we decided to go down onto the beach. Clare insisted on getting her feet in the sea if it was the last thing she did. The beach was pebbly, crunching underneath my trainers, with little bits of sea glass shining underfoot. The sea looked wonderful - smooth and silky and periwinkle blue. Clare asked if I would like to go for a paddle too; I initially declined, explaining that I hated the feeling of wet feet in socks, but then realised I couldn’t resist either.

We took our shoes and socks off and waded into the water, shrieking half in delight and half in shock at how cold it was. Benny bounded after us, unsure at first but soon realising how nice the water felt. We splashed out and gingerly tiptoed across the pebbles. I noted how much Clare was wincing. After our paddle, we sat down to dry our feet and scrabbled around in the rocks for sea glass to take home. Clare showed me the redness and mottling which appeared on her feet after walking across the gravelly sand, telling me that she was going to pay for it, but it was worth it. Benny bugged us to throw a piece of seaweed for him. We gazed out across the water in contented silence.

We chatted about our shared love for fossils and pretty rocks as we put our shoes on and headed back along the beach, stopping every so often to pick up an interesting pebble to add to our respective collections. I thought back to a remark she had made earlier in the day, that she was old enough to be my mum, and I realised what an odd pair we must look, and that passers-by must think she was my mum, or my aunty, or some other relation. We headed back up the steep incline to where the car was parked, pausing occasionally to allow Clare to catch her breath. I could tell how tired she was and felt oddly proud that after everything that had happened, we managed to have the day out that we had wanted so much. She was beaming.

The above example shows how crip time operated in the lives of my participants. On this day, our plans changed multiple times. They were cancelled, then altered, and then altered again. This jumping around became a key part of my method; thinking about cancelled plans counted as data as much as those plans which were fulfilled. Much of what is important in the above vignette is the kind of ‘flex’ I experienced when making plans with Clare. Whenever we planned to do something, it was not at a fixed point in the future but instead something that needed to be negotiated according to how she was feeling.

What I would like to emphasise here, alongside the flexibility in plans that was always built into my fieldwork, was Clare's orientation to time. When she texted me that morning, she was thinking about how she would feel later in the day and as she was already feeling unwell, she had changed her plans accordingly. When it got to later in the day, she felt well enough for us to go out and thus our plans changed spontaneously. Similarly, when we went for a paddle in the sea, Clare anticipated the pain she would feel from doing so with the same logic as Thelma when she got on the carousel; that it was 'worth it', but she would pay in pain in the future.

This idea of 'worth it' pain was key to how my participants understood their pasts, in relation to their futures. Actions in the present were weighed up against how they might make a person feel the next day, or the next week. Only those actions which reached a certain threshold – either by bringing the person joy or being necessary for survival – were deemed 'worth it'. These actions happened regardless of the pain they might cause. Here, it is again clear why Whyte (2002)'s concept of subjunctivity and illness has had such impact on medical anthropologists, and how it can be used to draw attention to the motivations people who live with chronic illnesses have as they look to the future. The 'chanciness' that comes alongside chronic illness means that while pain is likely to happen in the future, this pain is always uncertain.

9.1.2 'Pacing'

In the non-pharmacological management of chronic pain, sufferers are encouraged to employ a technique called 'pacing' (NHS, 2021). The rationale behind 'pacing' is to ensure that energy is distributed evenly throughout the day, to avoid the 'boom and bust' cycle of behaviour which seems to commonly accompany chronic pain states. For example, if a person has household chores to do, 'pacing' techniques would encourage splitting these into 5-minute sections. In between each section of activity, a person is advised to build in 'rest periods' to allow the body to recover.

This 'self management' is akin to the 'adherence time' described by Benton *et al.,* (2017). Although writing about the pharmaceutical management of HIV/AIDS, parallels can be drawn between their field observations and my own. They write:

> 'treatment adherence entails syncing daily life to adherence time, planning one's routine around dosing schedules and within the limits of a bureaucratic apparatus' (Benton *et al.,* 2017: 7)

In the same sense, the idea of 'pacing' reflects many established ideas within biomedicine around how a person with chronic pain *should* behave as they move throughout their day. By not 'pacing', patients were seen as being in direct contravention of medical advice. During my research, this advice was given in tandem with the move by NICE to advise that pharmaceuticals should no longer be prescribed for the management of chronic pain. Often, after the removal of these medications, as can be seen through Thelma's story in Chapter Five, the options left to many people living under the diagnosis of chronic pain were either to use 'pacing' as their sole pain management option or seek pharmaceutical pain relief elsewhere, using unofficial routes.

For my participants, ‘pacing’ was often something they could only dream about doing. Working and other life responsibilities, both inside and outside the household, often thwarted any attempts to manage their pain in the way advised by clinicians. When I spoke to Ella about her new job and her upcoming wedding, she told me that she felt like she was *‘playing with the devil’*, referring to the stress she was under trying to juggle so many things at once. She went on to tell me that *‘being well is a balancing act’*, one that she was currently failing at. Similarly, Thelma’s responsibilities as a single mother meant that often her children’s needs came before her own. For her, ‘pacing’ was not a possibility, and being told she needed to do so to avoid pain was not helpful. As I spoke to people on this topic the same questions emerged repeatedly. How do you ‘pace’ when you have children, or a job, or both? How do you anticipate and plan for rest in a future that has no certainty of being restful?

However, the idea of ‘pacing’ certainly influenced how participants viewed the future, even if they could not implement the techniques in their lives fully. Janet told me about the impact *‘learning to live with her pain’* has had on her life. Over Zoom, she described to me how everything she does is in anticipation of the next day. *‘If I overdo it, I suffer the next day’* she explained to me. As we spoke, she described to me how important it was for people with fibromyalgia to *‘know their own bodies’*, and accept their limitations. For Janet, ‘adherence time’ formed an integral part of how she lived her life. Her movements and decision making were shaped a the line that she understood existed between ‘doing enough’ and ‘overdoing it’.

Similarly, Ivy, who had lived with chronic pain for over 40 years, told me that *‘people with chronic pain… we live in the future’*, always planning and making adjustments in their lives. As described in Chapter Seven, Ivy’s life was oriented around her medication schedule. The weekly replacement of her buprenorphine patch and the taking her morning medications, which she kept in her fruit bowl, shaped her life. She described this need to live in the future by telling me that whenever she goes anywhere, she thinks to herself *‘right, where am I going? Can I sit down? Will there be toilets?’*. This constant planning and anticipation demonstrates how the future, even if just the next few minutes or hours, often bears down upon life.

9.1.3 The consequences of ‘overdoing it’

Ivy’s idea that people with fibromyalgia ‘live in the future’ is something I saw many times. People’s lives were shaped around the limitations placed upon them by their diagnoses. However, I also saw many instances where adherence to ‘pacing’ was left behind. This was done in full knowledge and acceptance of the consequences; sometimes, seizing and reclaiming the present was more important, despite the potential for pain that emerged from doing so.

In the support groups I attended there was a running joke that certain members of the group ‘did too much’ and that the workload needed to be split more evenly between those who were more physically able to do certain things. On one of the first sessions I attended, I witnessed a joking argument between two group members which was centred around who was going to do the vacuuming. Both women were fighting to be able to use the hoover, to help clean up after the session. I understood that this was so the other woman could sit down. Eventually, George (the only member of the group beside me who did not have chronic pain) split the two ladies apart, saying with frustration that *he* would be the one to do the hoovering, as they both should be resting and not moving heavy vacuum cleaners around.

To return to the two vignettes that came earlier in this chapter, I want to emphasise the choices made by Thelma and Clare to do something enjoyable that was almost certain to cause pain. I saw these choices made repeatedly and understood that my participants were cognisant of when and why they had done so. By going against medical advice, these women had begun to challenge some of the parameters of their diagnosis (and subsequent treatment plans), which had put limits on their activity levels and their potential to do what they wanted, when they wanted. By making an inadvisable decision and forgoing 'pacing', these women challenged the medical advice they had been given and instead placed attention on their needs to live an enjoyable life in the present.

However, worries about the consequences of 'overdoing it' still imbued much of the way participants viewed the future, even if the decision to overdo it was made knowingly. On one visit to Chloe's house, I was told with both excitement and apprehension that her and her partner were going away to celebrate his birthday the following night. *'It's gonna kill us'* she told me, following up the statement with a story about a party she had gone to the previous Saturday as evidence for what the future might bring. After the party, no taxis home had been available, so she had decided to walk. She described to me how every step had been *'agony'*. On that night she had ended up sleeping on the sofa. Her partner had needed to bring her a wet flannel so she could clean her face from that position before collapsing into sleep. Past experiences of 'overdoing it' (consciously or not) impact, but do not necessarily change, the way people navigate decisions about the future. In fact, past knowledge of what happens after 'overdoing it' only seemed to provide Chloe with preparation for what the future might bring.

9.2 Past, present and future joy

Day-to-day decision making while living under a diagnosis of chronic pain always has an orientation towards the future. Subjunctive ideas about what 'might' happen if an action is undertaken are ever-present. Whyte (2002: 186) argues that by exploring how people live in the subjunctive, it is possible to further understand: 'the intentions, **hopes** and doubts of people looking toward an immediate future'. Similarly, in the final chapter of *Feminist, Queer, Crip*, Kafer (2013:45) makes the central aim of the text explicit, describing a future that '**imagines** disability differently'.

Here, I pull together theoretical strands from both medical anthropology and disability studies. The commonality is the focus on the 'hope' for 'imagined futures' that occurs in both quotes presented above. While often limiting, these futures can also provide avenues for hope, and so can be considered alongside the literature on hope presented in my literature review. Accordingly, in this last section of the final ethnographic chapter of my thesis, I want to imagine a more positive, utopian vision of what living under a diagnosis of chronic pain *can* look like. As discussed in the introduction to this chapter, much of this thesis has focused on the more violent aspects of living with chronic pain. What I want to do now is explore the hopeful acts that I have seen exist alongside this despair. How do people 'live well' while living under a diagnosis of chronic pain? In what ways are narratives about disabled lives challenged by the actions undertaken day to day?

Although I spent much of my fieldwork discussing pain, I also spent a lot of time having fun with participants. Over Zoom, in various stages of Covid-19 lockdowns, I laughed and joked with women I had never met in person. We shared cups of tea over the screen and provided each other with company that many people were sorely lacking during the pandemic. Often, these encounters would be the most social contact either of us had on a given day, and so became important beyond the boundaries of my research.

After restrictions lifted, I began to socialise in person with some of these women. I went on regular dog walks. I went to cafes, museums, and to the beach. I visited people in their homes, sitting with them for hours and talking about childhoods, memories of favourite holidays, and extended family gossip. Visits were punctuated by hot drinks, tangential conversations, family members calling round unexpectedly, and pets requiring attention. One of my favourite memories of these visits was Benji, Ivy's cat, sitting squarely on the notebook I had brought with me to take fieldnotes in. Neither of us had the heart to try and move him, and so my line of questioning moved away from chronic pain and onto the gossip from Ivy's granddaughter's birthday party.

Figure 11: Benji, Ivy's cat, eyeing me up for a treat

Figure 12: A visit to the Hancock museum in Newcastle with Thelma, Bethany and Georgina. The girls had wanted to document my encounter with the T.Rex.

When I finally managed to attend the in-person support group meetings in autumn 2021, I was surprised to find that much of the group activity was centred around gossiping and giving each other tips on pain management, all while doing arts and crafts. At these meetings, despite lacking any creative skill, I found myself getting very taken in by the different projects that were offered up to me. Alongside making things and helping others make things, I took part in curling tournaments, played seemingly endless games of bingo, ate too many cakes, attended traditional 'pie and pea suppers' and gossiped with women 40 years older than me about people I had never met. While conversations about chronic pain were very important, I found that a lot of my time was spent crafting, gossiping and drinking tea.

Figure 13: A flannel spaniel I made during a support group, my fieldnotes discarded behind.

The following examples demonstrate how joyful moments can, and do, form part of life under diagnosis. Rather than lives being centred around chronic pain, I saw chronic pain being pushed aside to make room for life:

9.2.1 Zoom tomatoes

Call with Janet, Excerpt from fieldnotes 21.6.21

We chatted a little more and I asked how the garden was doing – 'the veggies are doing amazing' she told me, smiling. She flipped the camera round on her iPad and held it through the window so I could see into the garden. I shouted out the veggies I could see – 'beans, lettuce... hanging tomato?' and she confirmed that that was what she had been growing. The camera flipped around back to Janet's face, beaming with pride, and she told me how she'd grown them all from seed, calling the plants 'my babies'.

Every time Janet and I spoke, we talked about how *'her veggies'* were doing. I learned about them from when they were seedlings, right up until they were harvested. It was through these conversations about her vegetables that I got to know more about Janet as a person, beyond her diagnosis. She had experienced the loss of her father in the year prior to taking part in my fieldwork, and was trying to navigate this grief. Looking after the vegetables brought her immense joy; by doing so she got out into the fresh air and was able to feel proud of something she'd done independently.

More generally, caring for something (plants, animals, children and grandchildren) was presented to me as one of the great joys in life and one of the ways people 'kept going' through the simple acts of care described above. For Janet, caring for these vegetables (watering them, checking them for pests) introduced an element of reliability and predictability into her life, which came alongside the 'pacing' she practiced daily. In this sense, while chronic pain created some of the everyday rhythms of her life, these rhythms were also tempered with other things, such as caring for her garden.

Furthermore, the friendship Janet and I formed around her veggies shaped a lot of the conversations we had about her pain. Often, we would talk about 'normal' things over Zoom, and then she would bring in how her pain impacted this. She would tell me how she needed to be careful while gardening to avoid hurting herself or causing more pain in the long run. At the time of writing this chapter (December 2022), we are still in touch sporadically over email, and I hope to be updated about her vegetables once the worst of the winter has passed.

9.2.2 The curling match

Chronic Pain Care, 1.11.21

Iona suggested playing a game of curling and everyone was very keen. I'd not played before and was slightly amused by how serious it all seemed, people seemed very competitive about it! A target, printed on a large sheet of paper, was placed on the floor. I was allocated to the red team, as I hadn't been present for the seemingly endless ongoing tournament that had been happening before this.

Before we started playing, George, dressed in full vampire gear, sidled up to me and said something completely unintelligible. It was the morning after Halloween and everyone had come dressed in costume. I'd never imagined Dracula to have a heavy Durham accent before. I blinked at him and asked what on earth he'd just said, and he began to laugh at me. He explained that he was speaking pitmatic and asked me if I knew what that was. I said I absolutely did not. He went and picked up his phone and showed me something on Wikipedia. He explained that pitmatic was a dialect spoken by miners in County Durham, and I came to realise he had just been very rude to me without me knowing. I scrolled down the page and laughed, happy that I'd just been taught something I'd not even known existed before, and learned something new about the area I was in.

After that nugget of information was shared with me, the very serious business of playing curling began. People were spread around the game in various positions, some found it more comfortable to stand, some needed to sit, some needed to lean on their canes. It was interesting to see people move, as a lot of the times I'd visited before everyone had been sitting around tables, completely sedentary. The dark horse of the match was Edna, who is about 85. She had to lean on her cane to push the 'stone' towards the bullseye, but she almost always hit the mark. George and Mildred, clearly seasoned curlers, were being very competitive. Their little grandson, who was with them today, was the star of the show. I was perched with my back to the radiator as I was freezing, stood in between Mildred and her grandson and Maeve. It was clear to me how much Mildred adores her grandson; she was pointing out his beautiful eyelashes and how good and well behaved he was. The relationship Mildred had with her grandson was obviously very special and was based off unconditional love.

The curling was tense. I was useless and no help to the red team, but was still pleased when we won. I was feeling tired at this point – I'd not slept well the night before and had eaten too much cake. There was also a *strange gloom in the sky that only happens when it gets really, really near to winter, and it starts to feel like you should be bedding down and hibernating. We began to clear up – I always feel a bit awkward at this point because I don't know what I should be doing. Whenever I offered to help, I got brushed away and told it wasn't my job.*

During my time attending Chronic Pain Care I learned more and more about the importance of the ongoing curling tournament I had inadvertently become involved with. To participate, everyone needed to stand up and move into teams, and often, the actual act of playing was painful, so people would take breaks halfway through to sit down. It was clear that participating in curling was a choice that was made simply because *it was fun.* None of the events that occurred in the above vignette were centred around what it was like to live with chronic pain. They were undertaken in the pursuit of having a good time.

The social interactions I was privy to showed social relations of care. When George spoke to me (rudely) in the local mining dialect, it was clear that he wanted me to be able to learn more about the place I was researching. Indeed, later that day he offered me his collection of County Durham history books, should I find them useful. Similarly, George and Mildred's grandson was a favourite visitor to the support group, always being fussed over (and given cake). As people attended the group more regularly, they got to know each other but also each other's families too. From here, they became invested in each other's lives. Sometimes, they even became like extended family to one another. For example, during group activities like the curling match, lifts to and from sessions were arranged between members and other activities during the week (outside of the group) were also planned.

As people got to know each other more intimately, the experience of living under diagnosis became secondary, with ideas of 'looking after each other' at the forefront instead. Imbued throughout all the group's interactions was a subtle awareness about the various needs of others: a soft chair, a walking stick, to not wash up the teacups. While 'pacing' and the constraints of 'adherence time' were an important part of how people spent and allocated their time, perhaps the most meaningful things I observed were the fun and caring social relationships that occurred during support group meetings. These occurrences were, in a sense, future oriented. They allowed people to plan things which were not related to their diagnosis, and instead created a future where community and social interaction took prominence.

9.3 Conclusion

This chapter has explored how people understand their future(s) while living under a diagnosis of chronic pain, and how they make everyday decisions based upon the question of what 'might' happen in the future. Using the concept of 'subjunctivity', alongside perspectives from disability studies, I have demonstrated how living under a diagnosis of chronic pain impacts the way the future is experienced and perceived. Through all of this, it must be emphasised that this potential future isn't solely dictated by chronic pain, but is also influenced by the need to care for others and build community.

The first part of this chapter addressed the importance of 'trade-offs' and the concept of 'pacing' to how the future is navigated. I have outlined how the approach of 'pacing', usually presented as the best way to manage chronic pain without potentially addictive pharmaceuticals, is sometimes at odds with the reality of living under diagnosis. By not ‘pacing’ (and therefore not adhering to treatment protocols for pain and going against biomedical advice), participants see themselves trading off a pain-free tomorrow in exchange for having fun ‘in the moment’. They called the pain they might feel in the future ‘worth-it pain’. For the women who took part in my research, the prospect of ‘overdoing it’ always hung over them, and there were direct links between the choices made in the present and the potential pain felt in the future.

The second part of this chapter focused on what people did with this knowledge, and how they made these choices. It looks to how people resist the constraints placed upon them by the pain management strategies promoted by the healthcare they can currently access. Furthermore, it explores how the avoidance of pain was not always the primary aim of my participants, and instead the driving force behind decision making was the need to have fun, care for others and build community.

The purpose of this chapter is to emphasise the futures people who live under a diagnosis of chronic pain envision. While the chronicity of pain states did dictate how futures were planned, often the potential for pain is ‘worth it’ to have fun in the present. Throughout this final main chapter, I have aimed to show how people (both individually and as communities) create lives which are full, and not exclusively dictated by a diagnosis. As I have described throughout, often the urge to do something, experience something, or have fun with loved ones was truly the driving force which led people towards the future.

Although the future under a diagnosis of chronic pain is always placed in the subjunctive (Whyte, 2002), thinking with crip time might allow us to see how we could build a world that approaches chronic pain and other forms of disability in a way that ‘bends the clock to meet disabled bodies and minds’ (Kafer, 2013:27). In support groups, people worked with each other to bend the clock, and to create environments where everyone could take part in activities without experiencing too much pain. Individually, people found ways to bring small joys into their lives which made the future worth living. In the next section, the conclusion of this thesis, I consider the building of these futures further.

10 Chapter Ten: Conclusion – Chronic Pain Futures

As I write this conclusion in March 2023, I am sitting in a private medical clinic in Dusseldorf, Germany. I am here with my partner, James, while he seeks experimental treatment for the brain cancer he has been living with since 2021. For much of my PhD, my academic and personal life has collided in many unpleasant ways. I have seen, brutally close up, what it is like to navigate healthcare in the UK when a person has a rare or poorly understood condition. I have seen what it is like to come up against the restrictions of NICE guidelines and be told that there are few NHS treatment options left. I have seen the endless bureaucracy that is required when seeking state benefits. I have seen what it is like to live with fatigue and pain in the every day, and to face discrimination for not fitting accepted notions of what 'disability' looks like.

Fortunately for James, and for myself, we have been able to leverage the considerable social and economic capital around us to facilitate this trip to Germany for what might be lifesaving treatment. Many other people living under the same diagnosis as James do not have this option. I have seen the importance of hope, and the enactment of the subjunctivity (Whyte, 2002) discussed in the final chapter of this thesis. What has kept me going is the possibility of a better future: for James, for myself, and for the people who took part in this research. I don't know what will happen after the treatment finishes and James and I leave Germany. The future is wide open. It is a series of question marks, possibilities and 'what if's'. However, what is certain is the role a mixture of hope, socio-economic privilege and good fortune has played in getting us here, and how it is propelling us towards an unknown future.

By bringing my own life into the end of this thesis, I aim to show the importance of what I have documented throughout it. Rather than simply relating to a specific group of people, in a specific place, at a specific time, the insights I have gained through the generous engagement of my participants can be applied more broadly to improve the lives of those 'living under' many different diagnoses. However, this must come with a caution that I have tried to highlight persistently throughout writing; access to care, and indeed to health itself, is distributed inequitably.

In this conclusion, I first revisit my research questions and summarise how I answered them. Here, I reiterate that the findings from my fieldwork exist first in the shadow of the Covid-19 pandemic, and then in the shadow of illness and disease in my personal life. As I hope has been clear throughout this piece of work, my doctorate never went as planned, but I was able to generate a deep understanding of life under a diagnosis of chronic pain. Necessarily, this has shaped the conclusions I have been able to draw from the questions I asked.

After reflecting on my research questions, I discuss the key theoretical and practical conclusions that emerge from this thesis. This thesis theoretically engages with a growing body of work on disability anthropology. My first theoretical contribution, emerging from disability studies, concerns time, causality and disability. My ethnographic data has shown the complicated relationship between chronic pain and time. I argue that this understanding might contribute to how anthropologists theorise relationships between violence and pain as being entwined and cumulative, rather than linear. Further to this, my second key theoretical conclusion argues that it is essential for medical anthropologists to 'take biology seriously' (Wilson, 2015: 13) when listening to, and theorising, how people talk about their pain. Thinking with biology can offer new, nuanced, ways to consider chronic pain. Finally, my third key theoretical conclusion considers how the fluidity of the substances used to treat pain can contribute to both the anthropology of pharmaceuticals and the anthropology of drugs. I then offer two main practical conclusions; firstly, that clinicians need to take structural violence into account when treating chronic pain, and secondly that large-scale social welfare reform is needed in the UK to create a just and disability-inclusive welfare state.

Rather than simply documenting the pain and injustice faced by my participants, the last section of my conclusion looks forward and imagines the potential for chronic pain futures oriented towards justice and care. Ethnography is not a statistical method – it cannot be used to predict a certain medical future or provide a prognosis for others. What it can do is demonstrate how individual illness is enmeshed with larger social forces, allowing us to consider how this collision plays out in the everyday. Anthropological inquiry allows us to ‘conceive of a humanity yet to come’ which presents possibilities of ‘thinking beyond the profound fissures and limits of the present’ (Pandian, 2019: 4, 14). The very last section of my thesis is dedicated to this ‘thinking beyond’.

10.1 Returning to the research questions

10.1.1 What is everyday life like for people who live with chronic pain? How does living under a diagnosis of chronic pain in the everyday alter a person’s relationship to time?

The experience of everyday life while living under a diagnosis of chronic pain can be summarised in one word: unpredictable. As is mentioned several times throughout this thesis, I believe that the data I did not gather due to this unpredictability was extremely important. Missed and forgotten Zoom calls, cancelled plans, ‘bad days’, sudden ‘flare ups’, last minute trips to the beach, and phone calls taken on trains in between shifts, are all demonstrative of the realities of the way chronic pain fragments time. These ‘glimpses’ of life with pain were equally important to the conclusions I have drawn whilst conducting more traditional, in person fieldwork. By putting these fragments of everyday life together as a narrative, I was able to further understand how time operates while living under a diagnosis of chronic pain.

In this thesis, I have considered at length how my participants’ ‘lived under’ a diagnosis of chronic pain (Martin, 2007) and have considered the point of diagnosis as being a metaphorical boundary between past and present. Theoretical links between chronic illness and time are not new, having been discussed at length within both medical anthropology (Manderson and Smith-Morris, 2010; Manderson, 2020) and disability studies (Kafer, 2013). This thesis has examined the intersection of these disciplinary perspectives, considering how Kafer’s (2013) crip time operates in the lives of those living under the diagnosis of chronic pain. Using ethnographic examples I have documented how chronic pain can alter a person’s experience of the everyday, which I have shown through the very structure of this thesis.

In the first section, ‘The Past: or, what happened before’, I illustrated that the point of diagnosis has great meaning and can serve as a marker between the past and the present. Sometimes the diagnosis histories told to me held equal, or more, narrative weight than experiences of trauma and violence in the past. This is important to consider when doing research with those living under a chronic pain diagnosis. Talking to people about their pain involves an understanding that everyday life is often lived simultaneously ‘looking back’ and with the future in mind.

In ‘The Present: or, life under diagnosis’ I detailed the many ways chronic pain can alter the experiences of everyday life. These aspects of 'the present’ come under the umbrella of ‘living under’ diagnosis (Martin, 2007). In this section, I first looked at how chronically ill women exist at the ‘borderlands’ between sickness and wellness, and as such must learn nuanced ways to navigate health systems. I then considered the simultaneous impact of gender and sex on life under a diagnosis of chronic pain. After this, I explored how different substances are used to manage pain in everyday life, and how these substances are taken according to ‘what works’. Finally, I demonstrated how people living under the diagnosis of chronic pain in the ‘traumatic landscapes’ (Proudfoot, 2019) of North East England participate in forms of biocitizenship that might allow them to access state welfare benefits. Through these examples I have shown how the experience of ‘the present’ is deeply entangled with life under diagnosis.

In ‘The Future (?)’ (within which this conclusion is placed) I have outlined the concept of ‘worth-it’ pain and demonstrated how (as Ivy said) *‘people with chronic pain… we live in the future’*. For people living under a diagnosis of chronic pain, everyday life is a constant negotiation of what activities are ‘worth it’, despite the pain they may cause in the future. In this sense, imagined futures loom over the everyday, and a person’s relationship to time becomes altered through this delicate mediation.

10.1.2 What social relations exist between chronically ill people? What is the role of ‘support groups’ in managing chronic pain?

The relationships my participants had with each other were extremely important. Living under a diagnosis of chronic pain can be very isolating, and feelings of loneliness were not at all uncommon. However, the role of support groups helped to ease some of this loneliness, even if this contact occurred only through a screen. While spending time with participants during lockdown, and in the early months after restrictions were lifted in 2021, I heard how support groups on social media were a lifeline during the height of the pandemic. Every single participant recruited to take part in my research was recruited through a support group[12]. These groups were central to forging and maintaining social relations between groups of people with similar diagnoses, or clusters of symptoms.

As demonstrated in Chapter Eight, support groups (especially those held in person) were a place where biocitizenship emerged. Support groups helped people to manage pain through providing practical support and advice clustered around different diagnoses and symptom profiles. In Chapter Four, I have shown that support groups are a place where diagnoses can be questioned, clarified, or affirmed. At these groups, the boundaries of the looping effects which feed into various chronic pain diagnoses are stretched, moulded into new shapes, and re-formed. From here, tips and advice on finding substances that ‘work’ for particular forms of pain can be traded, alongside the provision of help and support in the groups themselves. Furthermore, in Chapter Nine, I

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[12] This, of course, begs the question of the experience of those *not* involved in support groups. However, this question is beyond the scope of the data I was able to gather.

demonstrated how support groups can be a place where people go to have fun, catch up with friends, and enjoy themselves without worrying so much about the future.

10.1.3 What social relations exist between chronically ill people, their doctors and the state?

Broadly speaking, the relations that exist between chronically ill people, their doctors, and the state are fraught with tension. Almost every one of my ethnographic chapters includes data about mistreatment and discrimination involving either clinical relationships, relationships between participants and the state, or both. While participants did also experience useful and compassionate consultations with clinicians, these were often overshadowed by many more difficult and upsetting encounters. In Chapters Three and Four, I have shown how people living under the diagnosis of chronic pain are often subject to 'epistemic injustice' (Fricker, 2009) when interacting with health professionals and seeking care for symptoms which are (at the time) unnamed or do not fit accepted biomedical models. This epistemic injustice often results in the disbelief of symptoms as being 'purely psychosomatic' and can delay the diagnosis process by many years. Furthermore, in Chapter Five, I demonstrated how, even after a diagnosis is obtained, relationships with clinicians can still be difficult, and are often navigated using *la facultad* (Anzaldúa, 1987). The challenges that emerged in the social relations built between my participants and their clinicians became especially difficult where the prescription of painkilling medications was concerned.

Much of the central section of my thesis is focused on how my participants interacted with the state, in various ways. As I hope is abundantly apparent, interactions with the DWP through the attempt to obtain various sickness benefits saturated much of my participants' lives. This is partially why the clinical relationships detailed above were so difficult; participants were not only seeking a diagnosis and medications to get better care, but also to evidence the 'correct' form of sickness to be eligible for benefits. As outlined in Chapter Eight, this evidence was crucial to even have a chance of obtaining benefits. In Chapter Eight, I have shown how relationships between my participants and the state involved a specific form of biocitizenship, which was obtained in many complex ways. Elements of this were foreshadowed in Chapters Six and Seven, through the biological narratives my participants held about their pain in relation to their gender, and through the ways they accessed, stored, and used different painkilling substances in idiosyncratic ways.

10.1.4 How are broader inequalities embedded in the chronic pain landscapes of North East England? How do these inequalities play out in people's lives?

This research question is central to the epistemic foundations of this thesis. Before I started doing this research, I wanted to understand how health inequalities play out in everyday lives. Throughout this thesis, I have repeatedly referred to the landscape of health inequalities in England more broadly, and especially in the North East. I wanted to add ethnographic detail to this data, and to place the stories my participants shared with me at the forefront of analysis. While writing, I have focused mostly on health inequalities through the lens of gender and class. This is due to the demographic qualities of the North East and also due to the pool of participants I was able to access during the pandemic.

In Chapters Three and Four, I summarised how gendered understandings of chronic pain aetiology can shape access to a diagnosis. In Chapter Three, I looked closely at how ideas about the links between trauma and chronic pain were navigated and understood by participants. In Chapter Four, I presented participants' own narratives of causality through a close reading of the diagnosis histories of Ivy, Ella and Jennifer, which all necessarily concerned gender. In Chapter Five, I expanded on this to explore how various forms of marginalisation combine to shape the care my participants were able to obtain *after diagnosis*. Most obviously, I devoted an entire chapter (Chapter Six) to exploring how the intersection of gender, sex and motherhood serves to shape the experience of living under a diagnosis of chronic pain. In that chapter, I argued explicitly that the gendered expectations placed upon the bodies of my participants, alongside biological understandings of female pain as 'natural', served to exacerbate and intensify the chronic pain states experienced by my participants.

Class is a more complex topic to address; the majority (but certainly not all) of my participants lived in deprived areas. As a consequence I have often used deprivation as a proxy for class. This was due to the background health inequalities data which informed my research being mostly oriented around index of deprivation. However, it was very clear how class and social deprivation influenced how participants navigated the world and how they understood its impact on their health. This was particularly apparent in Chapter Eight, through the example of the Consett incinerator protests, and through analysis of people's engagements with the welfare state. It can also be seen throughout the thesis more broadly; as above, every single one of my ethnographic chapters provides examples of how class and deprivation were embedded in people's experiences of living under a diagnosis of chronic pain.

However, it is not entirely useful to think about 'class' and 'gender' as separate variables each making their own independent contribution to the landscape of inequalities in the North East. It is most useful to think about gender, class and chronic pain in the North East through an intersectional lens (Crenshaw, 1989). The importance of this intersectional approach can be demonstrated through Thelma's awareness of her own identity as a '*disabled working class single mam of two disabled kids'*. It is not possible to separate all the parts of Thelma's identity from each other, instead they combine to create a specific profile of oppression which led, in part, to the experiences she had throughout her life. Inequalities play out in people's lives in intersectional ways. It is this intersectionality that can be used to best view the ethnographic data presented throughout this thesis and answer this research question.

10.2 Key contributions

10.2.1 Theoretical contributions

This thesis contributes to a growing body of literature theoretically oriented around 'disability anthropology' (Hartblay, 2020). By engaging with Hartblay (2020)'s call to work at the intersection of medical anthropology and critical disability studies, I have reinforced the utility of drawing from both these disciplines when researching with, and writing about, disabled people. I would urge other medical anthropologists working on disability to take this approach in the future. In this thesis, I have drawn from disability anthropology and critical medical anthropology from a feminist perspective. In turn, this 'critical feminist disability anthropology' has shaped the theoretical contributions I detail below.

By engaging with disability anthropology, I have drawn my first key theoretical conclusion, which concerns the relationships between chronic pain, disability, causality and temporality. As demonstrated through the structure and form of this thesis, living with chronic pain entirely changes a person's relationship to time. I have addressed this at length in 10.1.1 but here want to emphasise that medical anthropologists focused on chronic illness should think about crip time (Kafer, 2013) in the future. If medical anthropologists working on disability choose to be disability anthropologists, they will need to take temporality into account by necessity. By taking this approach, we can think not only about the societal limitations placed on disabled bodies, but also about how people maintain and sustain hope for a better future in potentially surprising ways. The possibility for a better future is something I will return to in the very final section of this thesis.

Ideas about time have also led me to consider the theoretical relationship between time, chronic pain and violence. In 'The Past: or what happened before' I outlined the complexity that leads up to a diagnosis of chronic pain, and have argued that the experiences (and implications) of violence in my participants' lives can be best aligned with Farmer (2004a)'s structural violence. I have illustrated the importance of thinking in different ways about violence and pain through my participants' own words; when telling me the origin story of their pain, they did not tell me about 'what had happened to them' in the past, but rather told me the story of 'how they were diagnosed'.

For my participants, experiences of violence existed not only in their pasts, but were an ongoing part of the present. This is important when thinking about the orientation of chronic pain and time; often the point of diagnosis served as a metaphorical boundary between past and present (or, living 'before' and then 'under' diagnosis). The women who took part in this research infrequently drew direct, singular, causal relationships between their chronic pain and their past experiences of violence. Instead, they viewed violence as something they had experienced, and continued to experience, throughout their lives. In this thesis, I theorise that chronic pain states are situated within environments of ongoing, and sustained, exposure to structural violence. It is important not to simply abstract the everyday experience of chronic pain back to the events of the past. By thinking structurally, it is possible to attend to broader narratives about the aetiology of chronic pain, while thinking with some (older) perspectives from critical medical anthropology concerned with political economy. We need to think about causality in context. In other words, chronic pain does not just flash into existence at a specific point in time; it is not the 'making and remaking' of the world (Scarry, 1985), but the production and reproduction of structural violence.

This links to my second key theoretical contribution; how I have written about these diagnoses with the importance of biology in mind. Although useful and interesting, critical perspectives on the reality of diagnostic categories were not all that important to this thesis. This is because thinking about their diagnoses critically was not something central to my participants' lives. In fact, as detailed in Chapter Four, a diagnosis was truly something my participants had to 'fight to get' (Dumit, 2006). By using Hacking (1995)'s 'looping effects' I have looked to the importance of this fight. By trying to 'loop into' the contested diagnosis categories which make up many different chronic pain states, my participants were able to align their symptom clusters with a biological reality, which was communicated and made more 'real' through the biomedical language of diagnosis.

By looking at how these 'looping effects' (Hacking, 1995) emerge I have also learned something about the embodied experience of living under these diagnoses. To have a diagnosis of chronic pain involves a constant (re)negotiation of the looping effects described by Hacking. As a result, women living with chronic pain live at the threshold between sickness and wellness. In Chapter Four, I have described how existing 'at the borderland' in this way often involves a complex negotiation of the world, to allow a person to demonstrate the 'correct' way of being chronically ill, and to get the care they desire. These negotiations manifest in what Anzaldúa (1983) terms *la facultad* – a special type of embodied, felt, knowledge that emerges through the experience of being marginalised. In this thesis, I have demonstrated how this deep bodily knowledge is mobilised to obtain care.

Anzaldúa's work has been incredibly important when theorising how participants move around the world, interact with healthcare professionals, and understand their various diagnoses. The intangible nature of chronic pain creates multiple border spaces that individuals must move across and in-between when navigating through their lives. In this thesis, I wanted to move beyond the ideas of liminality more traditionally used in anthropology – there was something different about the liminality experienced by my chronically ill participants which was felt somewhere in their bodies. It was felt as they moved through the world. As Piepzna-Samarasinha (2018: 185), when writing on Anzaldúa, puts it 'my illness opens the door to write in the nepantla [in the middle] place'. Anzaldúa's work has allowed me to bring together an understanding of how forms of marginalization impact the *embodied* experience of living under a diagnosis of chronic pain.

Looking to both 'looping effects' and *la facultad* can tell us something about the importance of biology and biological illness narratives when producing narratives around chronic pain. People 'loop into' different diagnoses, and learn to navigate these diagnoses in specific ways, by creating understandings of what is happening in their body. My ethnographic data shows the prevalence of narratives of biological 'malfunction' or 'abnormality' that are so often given explanatory power as being the cause or origin of chronic pain. For the women who took part in my research, pain narratives were grounded in their reproductive biology, explained through genetic theories (proven, or not), or grounded in past infections that did 'something' to their immune systems to trigger chronic pain states. Furthermore, as demonstrated in Chapter Six, these biological pain narratives were innately tied up with ideas of sex and gender, resulting in the idea that being in pain was just something 'women live with'. These narratives were also navigated by participants so that they could have their pain taken seriously by clinicians, and (as discussed in Chapter Eight) to attempt to prove some biological damage to their bodies in order to obtain state welfare benefits.

In this thesis I follow Wilson (2015) in arguing for the importance of taking these biological perspectives seriously, and thinking deeply about what they mean. The importance of biology to understandings of chronic pain is something that became clear when I looked at the chapters I had planned for this thesis as a collective. Biological explanations of pain were so important to my participants because biomedical narratives about the cause of chronic pain (and especially fibromyalgia) were surprisingly *not* grounded in biology. As discussed throughout this thesis, the cause of chronic pain was often abstracted to traumatic events which had occurred deep in my participants' pasts.

Thinking with and through biology in this way aligns well with more recent calls for a truly integrated biosocial anthropology (Ingold and Gísli Pálsson, 2013; Gibbon *et al.*, 2020). These ideas sit alongside contemporary anthropological work focused on microbiomes, holobionts, and multispecies perspectives on health (Benezra, DeStefano and Gordon, 2012; Fuentes, 2019; Lorimer, 2019). In this thesis, I focused on people's understandings and explanations of their own biology as a starting point to understand their pain, in their words. By taking these narratives seriously, I have demonstrated how my participants related their chronic pain to their bodies, in a way that often resisted what they had been told by clinicians. This can provide an interesting and timely counter to the narratives which frame chronic pain as a somatisation of a past traumatic event. This could produce a theoretical starting point for future pain research which looks to biology, and thinks with it, rather than away from it.

My third and final key theoretical conclusion relates to how medical anthropologists think, and write, about pharmaceuticals and other drugs. As outlined in Chapter Seven, what was important to my participants when it came to treating their chronic pain with different substances was *what works.* Academic literature on the anthropology of pharmaceuticals and the anthropology of drugs tends to treat these two classificatory groups as entirely different entities, with different bodies of literature to accompany them. Because of this, some depth of understanding is lost when trying to understand *what works.* Insights from Hardon and Sanabria's (2017) updated anthropology of pharmaceuticals are very helpful when thinking about fluidity and 'matter flow' in regard to this. These insights can help to bridge the gaps between these two disparate bodies of literature. Chapter Seven builds upon this idea of 'matter flow' and uses the term 'substances' to draw theoretically from both the anthropology of drugs and the anthropology of pharmaceuticals. When writing about how substances are used, it is important to move beyond binaries of 'legal/illegal', 'prescription/non-prescription' or indeed 'pharmaceutical/drug'.

Thinking about 'what works' allows for some fluidity in understandings of efficacy. This is important for two reasons. Firstly, it highlights the importance of biological understandings of how substances work in and on bodies. It does not matter whether the substance used to manage pain is cannabis butter or a buprenorphine patch; what is important is the feelings of relief experienced by a person, and how this relief is articulated through biological language. Thinking about how people describe what is happening in their body is what is necessary here. By looking at how efficacy is articulated through biomedical and biological language, it is possible to think more deeply about when people take substances, how they take them, why they take them, and what they do.

Secondly, thinking with substances could be more freeing, and allow for understandings of substance use and efficacy to be further expanded out *beyond* bodies and into the world around them. This is something akin to Landecker (2016:22)'s 'biology of history' which describes 'how human historical events and processes have materialized as biological events and processes and ecologies'. Although describing how antibiotics 'bleed' out of bodies and into ecosystems and environments, Landecker's argument is that we need a 'perspective on biology that is not contained in different organisms' (Landecker, 2016:43). In other words, we need to look at the history of biology in order to gain broader understandings of use and efficacy. This is something I inadvertently did when thinking about *what works* as my epistemic end point. By documenting the many ways in which my participants learned to navigate the benefits system through accessing (or not accessing) and taking (or not taking) different substances, in different ways, I have highlighted how looking at 'what works' can help us understand the efficacy of these substances *within and beyond people's bodies*. Thinking about substances can help medical anthropologists to consider use and efficacy as being situated and negotiated within broader political economies. If a substance allows a person to obtain state benefits or helps to articulate the biological cause of their unknown illness to another, then it can be considered efficacious. In this way we can think of efficacy as being situated outside of bodies, as well as within them. These 'local biologies' (Nading, 2017; Niewöhner and Lock, 2018) emerge and change not only within bodies themselves, but within social systems more broadly.

10.2.2 Practical contributions

While writing, I struggled immensely with suggesting practical conclusions. When I thought about the sum of what I learned from doing this fieldwork, the conclusions I felt I could make with confidence seemed small and ineffectual. After talking it over in supervision, and with friends over multiple glasses of wine, I realised the nagging doubt I had was that making any practical suggestions was (for want of a better word) pointless. What use is a PhD thesis against a deeply embedded system like the British welfare state? What difference would writing this thesis make in the aftermath of over a decade of austerity? How can I make recommendations for care and support that would, in likelihood, never materialise? Those around me affirmed that even writing the words down was important, and that I needed to do it to do justice to the work I claim to do as a feminist critical disability anthropologist.

There are therefore two main practical conclusions to draw from this thesis. The first concerns the role of structural violence in people's lives, and how this violence is understood clinically. As discussed above, those living under a diagnosis of chronic pain often view its aetiology as being complex and rooted in some biological origin. Practically, I argue that clinicians and policymakers should not view experiences of trauma and violence, and the development of chronic pain, to be unidirectional, singular and unchanging. I have demonstrated that when looking at chronic pain it is important to think more specifically about structural violence and how it impacts the development and maintenance of pain states. This understanding should feed into how chronic pain is talked about, how it is understood, how it is cared for, and how policy is created about it. I hope that making this assertion helps to avoid some of the critiques levied at the concept of structural violence (Farmer, 2004a). By promoting knowledge of structural violence as a legitimate tool in clinical practice and policymaking more broadly, it would be possible to use it as a practical, rather than rhetorical tool.

The two chapters situated in 'The Past: or, what happened before' have all demonstrated how structural violence operates in the North East through interactions with healthcare professionals, through gender and sex, through access to different painkilling substances, and through access to state support and welfare. These conclusions are especially pertinent when thinking about healthcare encounters and the provision of services for people living under a diagnosis of chronic pain. By looking to the data on health inequalities in the North East, it is possible to understand the context of structural violence within which a patient might exist. While this structural violence persists, knowledge about it could provide a practical tool. It could help to understand how these inequalities impact a person's everyday life, what kinds of services might be practically helpful, and what kinds of services might promote further harm and violence. These services could take many forms, perhaps through the provision of disability friendly childcare, or the creation of flexible pain clinics which have an awareness of the potential for 'bad days' built in. Fundamentally, health and social care services should be accessible at every point. People with chronic pain should be treated as experts on their own bodies, and what works (or what does not work) should be understood through this expertise and listened to accordingly.

The second practical conclusion concerns the operation and administration of social welfare in the UK. Throughout this PhD I have explored themes of justice, and so it would be remiss of me here to not discuss the implications of how my participants interacted with the welfare state. Worries about access to state benefits permeated my participants' lives. These worries dictated how they interacted with health professionals, how they took their medications, and what work they did (or did not do).

The social welfare system in the UK needs to be reoriented with disability justice in mind. Assessments need to be based off knowledge about disability and resources awarded based upon need, rather than determined by tick box exercises that are not disability-informed. These systems contribute deeply to the structural violence my participants experienced. I want this PhD to stand in solidarity with my participants' experiences, and be aligned with research endeavours like the *Deaths By Welfare Project* to allow me to make a specific call for welfare reform and justice for those who have suffered at the hands of the welfare state (Healing Justice London, 2023*)*. My participants' lives were constantly overshadowed by worries about being the 'right' kind of disabled and fulfilling the 'correct' metrics to be eligible for benefits. In some cases, this prevented them from accessing the care they needed, being able to work, exercise or socialise in the way they wanted, or being able to be honest with their doctors about their medication use or care needs. Academics and policy-makers alike need to further recognise the limitations that the current welfare benefits system in the UK places on people, and call for reform from a health justice perspective.

10.3 Chronic pain futures

While writing up, I was adamant that I did not want this piece of work to simply act as an archive of chronic pain in the North East. This might seem odd, considering my choice of field site, research topic and method. In the final few words of my thesis, I want to think about how more habitable chronic pain futures could come into existence. Piepzna-Samarasinha (2018) has mapped how chronically ill and disabled people have come together to create communities and support networks based on a shared commitment to access and love. I saw these communities forged time and time again throughout my fieldwork. Many things were exchanged in the virtual and physical support groups I interacted with; advice, knowledge, medications, hugs, warnings. During 1-1 encounters, a shared commitment to a better future for those living under diagnosis was more than apparent. When asked why they wanted to take part in my research, each participant answered the same way. They simply stated that they wanted to make things better in the future for other people who had chronic pain. Medical anthropologists, clinicians, policy-makers and society more broadly can learn a lot from this.

Through this idea of 'dreaming disability justice' (Piepzna-Samarasinha, 2018), I decided to structure this thesis to speak to the lived experiences of my participants in the most authentic way I could. I have identified things that have happened to people, and continue to happen to people, through the structural violence that shapes life in so many parts of the North East. However, I have also shown how people continue to make things work despite all of this. What I experienced during my PhD, both professionally and personally, was the importance of 'living in hope' to the experience of long-term illness (Novas, 2006:291).

Through the support groups and the other ‘ways of hoping’ (Eaves, Nichter and Ritenbaugh, 2016) I observed, I have grown ever more convinced of the importance of ‘flex time’ (Kafer, 2013:27) to understand, and improve lives lived under the diagnosis of chronic pain. From the micro to the macro level, an understanding and awareness of this ‘flex’, which is already common knowledge to those who spend time in disability circles, is crucial to dream about chronic pain futures. When designing health systems, interventions or other services, the embodied knowledge of those living under the diagnosis of chronic pain is crucial to understanding ‘what works’. Sometimes, people can’t make appointments due to a ‘flare up’. Sometimes important plans get cancelled. Sometimes, a person might wake up feeling so well they refuse to spend another day carefully pacing and planning for the future. Instead, they choose to live in the present. All these things need to form part of the body of knowledge which exists about chronic pain. This thesis has documented some of this knowledge.

Furthermore, by understanding how people live full, happy, and fulfilling lives despite the many structurally violent forces that serve to restrict and oppress them, medical anthropologists (or perhaps more accurately, disability anthropologists) can simultaneously challenge these structures while acknowledging the legacies of ‘care work’ Piepzna-Samarasinha (2018) which has already existed for many decades. By looking at what people do to manage pain, and how they understand their own bodies in their own words, we can be future facing instead of oriented back deep into the past.

To reinforce my commitment to Hartblay (2020)’s call to create a disability anthropology, it seems only right to finish this thesis with a quote from Alison Kafer. Engaging with disability studies has helped to provide me with more insight to my participants’ lives than I could ever have dreamed of, and I am forever grateful for the strange twists and turns of fate which led to thesis following this path. Here, Kafer (2013) sums up what creating chronic pain futures could do more succinctly than I will ever be able to :

> ‘I desire crip futures: futures that embrace disabled people, futures that imagine disability differently, futures that support multiple ways of being’ (Kafer, 2013: 45)

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